EXECUTIVE SUMMARY

STUDY ONE: ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE: CAREGIVER INTERVIEWS

OBJECTIVES

The central purpose of this study was to identify differences among cultural groups in their beliefs about family caregiving and their views of respite services offered through the ADDGS program. The links between culture and belief systems, perceptions of service accessibility, and client satisfaction were explored in detail. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. Each of these dimensions of diversity was examined as a factor potentially affecting clients' beliefs about caregiving and views of program services.

METHODS

Telephone interviews were conducted with a culturally diverse sample of 377 client caregivers from the ADDGS Program using a computer assisted telephone interview (CATI) system. Eleven measures caregivers' beliefs about family care responsibilities and nine measure of caregivers' perceptions of access and/or barriers to service use were examined. Analysis of variance was used to examine differences between cultural groups in belief systems. Multiple regression procedures were used to identify predictors of client satisfaction.

RESULTS

- ➤ Differences were observed between ethnic groups on 9 of the 11 measures of caregiver beliefs and attitudes about filial care and responsibility. In contrast, only one difference in beliefs was associated with geography and two differences were associated with the relationship of the caregiver to the elder.
 - Whites reported lower levels affection for the care recipients and less adherence to family values.
 Whites also expressed the highest level of guilt for using support services and were least likely to endorse the responsibility of government to provide support services.
 - Hispanic/Latinos reported the highest level of adherence to family values and the greatest respect
 for elders. As a group, Hispanics/Latinos were also most satisfied with the levels of social
 contact they currently experienced and the level of help they received.

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- Black/African-Americans reported the highest levels of religiosity, the greatest strength of belief in God, and the highest levels of support from religious communities.
- Spouses expressed greater affection for the care recipients and greater obligation to provide care than did children or other groups of caregivers. Spouses also reported significantly less family conflict.
- Caregivers in urban areas reported greater respect for elders than those residing in rural areas.
- Cultural differences in views of services were identified for only two aspects of service programs.
 Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups.
 Notably, Whites reported the lowest levels for accessibility of services.
- > The most satisfied *day care* clients where those who: (1) received high levels of support and comfort from their religious congregation; (2) had clear expectations regarding the program services; (3) judged the respite services to be appropriate for the client; and (4) perceived the "red tape" to be minimal.
- Clients of *in-home* services were most satisfied when they: (1) had clear expectations regarding the program services; (2) perceived the respite services to be accessible at the times they need it; and (3) judged the program staff to be friendly.

IMPLICATIONS FOR PROVIDERS

The most significant findings from this study of client satisfaction are that differences in cultural beliefs do exist, but they are not important predictors of client satisfaction. Rather, four factors that are under the control of practitioners were found to be related to client satisfaction. These findings suggest that clients will be most satisfied when service providers:

- (1) convey to clients a clear understanding about what the respite program will and will not do in the way of providing care for the individual with AD;
- (2) reduce the amount of red tape associated with the program;
- (3) provide activities that caregivers believe to be appropriate for their family members; and
- (4) are flexible with the amount of service that is made available and the times at which it can be used.

STUDY ONE:

ASSESSING CULTURAL AND STRUCTURAL BARRIERS TO SERVICE USE— CAREGIVER INTERVIEWS

INTRODUCTION

As the population of the United States continues to become more diverse in age and ethnicity, there is growing concern for the care of disabled elderly persons. The provision of long-term care for elders with dementia, particularly those from traditionally underserved populations, poses complex problems at both the national and local levels.

Respite care is one type of family support service that helps the caregiver with the rigors of caregiving and may forestall institutional placement. However, a body of research suggests that uniform provision of respite service may not be appropriate for a population that is increasingly diverse. Instead, culturally dissimilar groups are likely to differ in their perceived need for, and evaluation of, respite services.

Cultural diversity is a broad rubric. Past research has identified patterns and preferences in the use of supportive services by caregivers of older adults that are associated with ethnicity, relationship to the care receiver (e.g., spouse vs. adult-child), and geographic location (urban vs. rural). Each of these factors identifies a different cultural grouping. Exactly how to interpret the effects of such cultural groupings on service use, however, remains uncertain because these factors each represent ascribed social statuses. Most researchers agree that when extraneous background factors that covary with ethnicity, relationship, or location are controlled (e.g., SES and need for service), any remaining differences in behavior can best be attributed to culturally-situated attitudes and beliefs related to membership in that cultural group (e.g., see Wolinsky et al., 1990). To date, the cultural attitudes and beliefs that might affect the use of community-based respite services have yet to receive any systematic attention.

The goal of this study was to examine a broad array of attitudes and beliefs about caregiving and aspects of service delivery to determine (1) whether these factors are differentially associated with memberships in the various cultural groups and (2) the extent to which these culturally-based factors are related to satisfaction with services.

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BACKGROUND

<u>Differences in Service Use Among Cultural Groups</u>

Over the past decade, there has been a growing interest in the differential patterns of service use associated with cultural diversity. In general, findings from studies of health and social service use have been somewhat contradictory with regard to differences in service use among ethnic groups. There is evidence of greater use of support services among Blacks/African-Americans (Miner, 1995; Wallace et al., 1992), lower use of services among minorities (Greene and Monahan, 1984; Kemper, 1992); and no differences in formal service utilization by race (Hing and Bloom, 1990; Krout et al., 1990).

To the extent that cultural factors refer to the social norms governing elder care, however, the notion of culture necessarily refers to more than just ethnic differences (e.g., see Kosloski, Young and Montgomery, 1999, for a review). For instance, despite their greater workload, spouses of older patients are least likely among caregivers to seek and use formal services (Stoller and Cutler, 1992). This tendency is even more pronounced for wives, who tend to resist using outside support to a greater degree than do husbands (Stoller and Cutler, 1992; Tennstedt et al., 1989). Similarly, there is evidence that rural elderly, as a group, use fewer community-based support services than urban elders (Coward et al., 1990; Krout, 1994). In short, there are clear differences among cultural groups, broadly defined, in the likelihood of service use.

Explanations for these "cultural" differences in patterns of service use have taken two general forms (Miller, McFall and Campbell, 1994). On the one hand, race, relationship status of the caregiver, and rural status are ascribed social statuses that are associated with significant differences in the distribution of economic resources, greater levels of need, and differential access to services. Most of the past research undertaken to investigate cultural differences in service use has focused on these differences (e.g., see Angel et al., 1992; Schur et al., 1995; Tennstedt, Chang and Delgado, 1998). On the other hand, ascribed social statuses such as ethnicity, relationship status of the caregiver, and rural status are also proxy variables for a constellation of differing cultural beliefs, attitudes, and expectations for behavior. Every group has expectations for its members, and it has been shown that expectations, attitudes, and meaning differ across cultural groups (Nydegger, 1983). Currently, however, very little is known

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about potential cultural differences of this sort. As Miller (1994) and her colleagues point out, there is a growing recognition that the association between culture and service use may reflect both differences in levels of need access to resources economic and differences in cultural beliefs (see also Belgrave, Wykle and Choi, 1991; Lockery, 1991; Mutran, 1985).

Culturally-based Attitudes and Beliefs about Services

Exactly how cultural factors might influence views of services and ultimately service use is still a matter of some debate. Two plausible avenues of influence emerge from the caregiving literature. The first possibility is that being a member of a cultural group somehow affects the way that caregivers perceive the need for services. The second line of thinking suggests that the manner in which services are offered can be culturally insensitive and thereby create barriers to use in by some groups.

Links between Perceptions of Need and Culturally-based Attitudes and Beliefs

Any background characteristic that locates a caregiver within a homogenous cultural grouping of people can potentially affect the way in which that individual views the need for support services. In the case of ethnicity, normative expectations about care of family members and beliefs about familial responsibility have consistently been shown to differ among African-Americans, Asian Americans, and other groups (Gelfand and Barressi, 1987; Markides and Martin, 1983; Mutran, 1985; Stanford and Lockery, 1983). To the extent that these beliefs about family responsibility translate into different perceptions of need for services it makes sense that these beliefs will also influence the use of a supportive service, such as respite care. That is to say because a client's perceived need for that service can vary considerably from one observer to another, it makes a difference as to "who" is determining need (Andersen, 1995). The cultural characteristics of the decision maker are likely to affect the perceived level of "need." This link between ethnicity and perceived need is consistent with empirical findings from previous work of the authors that supports the notion that ethnicity moderates perceptions of need to affect service use (Kosloski, Montgomery and Karner, 1999).

The issue, with respect to the relationship of the caregiver to the individual with Alzheimer's disease, is similar. There appear to be clear differences in normative expectations toward care

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of the elderly that are associated with different familial roles (Seelbach, 1978). For example, there is a considerable literature that documents differences between spouses and adult children in caregiving tasks and career patterns (Colerick and George, 1986; Montgomery and Datwyler, 1990). Spouses and children differ in their likelihood to seek and use support services (Kosloski and Montgomery, 1994). For example, if the wife of an impaired older person adheres to a normative belief that she is responsible for her husband's care, she may well experience serious guilt if she seeks the help of an outsider. Even if she does not feel guilty, other persons in her circle of friends or family may make a negative judgment about her role performance. A daughter who has her own family to care for and who is employed outside of the home may well experience stress if she were to care for her mother as well, but is less likely to experience negative social consequences if she were to seek outside help than would a spouse caregiver. Not surprisingly, spouses who are caregivers appear to make different determinations of need for support services than do adult-children (Kosloski and Montgomery, 1994).

Finally, the notion of a common culture with shared belief systems can be extended to include urban versus rural elders as well. A commonly held vision of rural life is that of a healthy, vigorous older couple living on a prosperous, immaculately tended homestead surrounded by a tight, intergenerational network of family and friends. In actuality, "there is very little evidence to support the popular, and widely accepted notion that rural elders have family networks that are stronger and more able to respond to their needs than urban elders" (Coward and Dwyer, 1991, p. 24). Nonetheless, to the extent that rural caregivers subscribe to this stereotype, they are less likely to use outside services.

Links between Cultural Beliefs and Perceptions of Service

Perceptions of services may also vary among cultural groups depending upon the manner in which the services are actually delivered. To date, within the Gerontological literature differences in client perceptions about access and barriers have been addressed almost exclusively with a focus on ethnic differences (see also Yeatts, Crow, and Folts, 1992, for a more comprehensive overview of the issues involved). A much broader literature exists in the area of medical service use where the competition for clients is more intense, and the viability of a service provider is more closely linked to how the service is viewed by those who utilize its services. In such arenas, client satisfaction with services, and the interpersonal relationships

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between providers and service users, are of central concern to service providers (Morishita et al., 1998; Sanders et al., 1998). From this perspective, the factors related to client satisfaction are important, regardless of ethnicity, relationship of the caregiver to the patient, or geographic location.

To the extent that the cultural factors are related to clients' expectations for services and client satisfaction with various aspects of service delivery, service providers can use this information to tailor their services to their specific clientele. In this manner providers can increase client satisfaction and solidify their customer base (Ware and Davies, 1983). The emphasis that medical providers have placed on client satisfaction is now emerging among providers of services for older adults (Geron et al., 2000; Simmons and Schnelle, 1999). For example, the quality of communication has consistently been found to an important determinant of client satisfaction (e.g., Bordy et al., 1989; Hall et al., 1988). Expectations for services are also important. Specifically, discrepancies between what clients expect to receive from a service and what they actually receive can significantly affect clients' evaluations of services (Falvo and Smith, 1983; Ross et al., 1995). In a similar manner, friendliness and interaction styles can affect satisfaction with service encounters (Greene et al., 1994). Not surprisingly, the extent to which the client trusts the service provider has been found to be a major determinant of satisfaction in health care delivery (Safran et al, 1998). Given the fragile condition of AD patients and their extreme dependence on their caregivers, trust is likely to emerge as an important factor in respite use as well. In addition to the foregoing factors, Yeatts and his colleagues (Yeatts, Crow, and Fouts, 1992) note the importance of factors such as service availability, attractiveness of the services or activities, and shared perspectives on care. Each of these latter factors has been shown to be related to both client outcomes such as satisfaction and cultural factors.

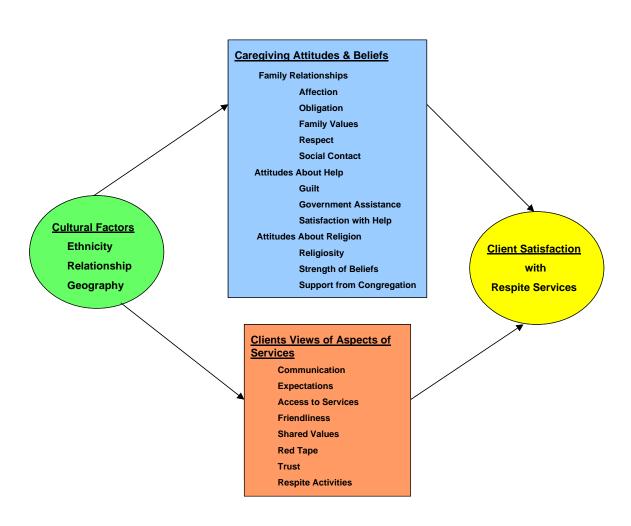
Conceptual Model

The two mechanisms by which cultural factors could potentially influence client satisfaction are depicted in Figure 1.1. As shown, the three types of cultural factors i.e., by ethnicity, relationship of the caregiver to the patient, or geographic location (urban vs. rural) can be viewed as factors influencing both caregiving attitudes and beliefs and perceptions about services. Caregiving attitudes and beliefs are grouped, in the blue box, under three headings:

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(1) Family Relationships which include affection for the elder, perceived obligation to care, family values, respect for elders, and desired frequency of social contact; (2) Attitudes about Help including guilt at respite use, attitudes toward government assistance, and satisfaction with help with caregiving; and (3) Attitudes about Religion which include religiosity, strength of beliefs, and support provided by religious congregation. Each of these attitudes and/or beliefs can differ. In turn, each of the attitudes and/or beliefs can affect the client's satisfaction with respite services.

Figure 1.1 Assessing Cultural and Structural Barriers to Service Use



The relationship between cultural factors and aspects of service delivery is also illustrated in Figure 1.1. Eight different aspects of service delivery, in the orange box, that are likely to affect clients' perceptions of respite services are investigated in the present study: communication, expectations, access to services, friendliness, shared values, red tape, trust, and appropriate activities. Consistent with the previous research from other service domains, these eight factors are also expected to influence clients' satisfaction with respite services.

METHODS

Purpose of Study

Study One was undertaken to evaluate each of the hypothesized relationships shown in Figure 1.1. Specifically the goal of the study was to (1) to evaluate possible differences in culturally-based attitudes and beliefs concerning the use of support services – particularly the use of respite services – and (2) to determine whether these differences are related to important outcomes of service use – specifically, client satisfaction with services.

Overview

Interviews were conducted with a culturally diverse sample of 377 family caregivers participating in the ADDGS program. Of these, 168 were white, 116 were African-American, and 91 were Hispanic. Approximately 35% were spouses and 45% resided in rural areas. Attitudes and beliefs about caregiving were assessed using 12 factors grouped under three broad headings dealing with Family Relationships (e.g., felt obligation to care), Attitudes toward Outside Help (e.g., guilt from using from services), and Attitudes about Religion (e.g., support from religious beliefs). Eight clients views of aspects of services were also examined including factors such as communication difficulties, access to services, and staff friendliness.

Sample Selection

Initially 1138 caregivers were identified from the ADDGS service records of eight states (California, Washington D.C., Florida, Maine, Michigan, North Carolina, South Carolina, Washington) as potential subjects for the study. Each state was selected based upon the criteria that it served specific target populations (Blacks/African-Americans, Hispanics/Latinos, and/or rural) and had consistently provided reliable data over the course of the demonstration.

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The initial sample pool included all White, Black/African-American, and Hispanic/Latino caregivers who met three criteria: (1) The family had utilized in-home respite or adult day care made available through the Alzheimer's Demonstration; (2) Complete demographic information was available for the caregiver and elder from project records; and (3) Current street address and telephone contact information were available for the caregiver.

Letters explaining the study and the benefits of participation were sent to each of the 1138 caregivers in the initial subject pool (see Appendix 1A). A set of response cards was also enclosed to aid participation in the interview. Approximately twelve days after the mailing of the initial letter, a trained interviewer placed a call to the caregiver to set an acceptable time for the interview to be conducted. If the caregiver was not reached by telephone on the initial attempt, up to 15 repeat attempts were made to contact the subject.

Of the original sample pool, 422 caregivers (37%) were ineligible for the study for a variety of reasons. Among those, 335 subjects (29% of original sample) were former caregivers of elders who were deceased or institutionally placed. Forty five (4%) caregivers had not used respite services within the last year. In 20 (2%) of the cases, the person who formerly provided care no longer provided assistance to the elder. Three of the elders did not have a caregiver, and eight of the caregivers were paid professionals. Eleven (1%) of the caregivers were excluded from the study because they had poor or no recollection of having used demonstration services. For some, this was due to the fact that they had signed up for services, but had not yet started using them. For others, their pattern of use had been infrequent, or had lapsed for such a period of time that they could not formulate an opinion regarding their satisfaction.

This left an eligible sample of 716 caregivers. Of these, inaccurate or outdated contact information that could not be updated by state officials precluded contact with 155 caregivers, reducing the sample to 561. Of these, 91 persons could not be contacted after 15 attempts. An additional 100 members of the original pool of subjects refused to participate despite their eligibility. This group included non-current caregivers that declined to discuss their past caregiving role and current caregivers who refused for other reasons. Some caregivers, particularly spouses, were ill or suffered from memory problems themselves due to advancing age. Others, especially adult children, declared themselves too busy to participate due to work

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or other familial obligations. Full interviews were completed with 370 caregivers invited to participate, or 79% of the valid sample who could be contacted. This final sample included current caregivers, and non-current caregivers who had used respite services within the twelve months prior to the interview. The final status of the potential subjects is shown in Table 1.1.

TABLE 1.1. DISTRIBUTION OF SAMPLE BY INTERVIEW COMPLETION

	N	%	_	N	%
Initial Sample	1138	100.0%	Suppl. Sample	14	100.0%
Interview Complete	370	32.5%		7	50.0%
Deemed Ineligible	422	37.1%		2	14.3%
Deceased/Placed	335	29.4%		0	0.0%
Non-Current Users	45	4.0%		1	7.1%
No Longer Caregiver	20	1.8%		0	0.0%
Client Self-Care	3	0.3%		0	0.0%
Paid Caremanager	8	0.7%		0	0.0%
No Recollection of Use	11	1.0%		1	7.1%
Unable to Contact	246	21.6%		5	35.7%
Wrong Contact Information	155	13.6%		1	7.1%
15 Attempts Unsuccessful	91	8.0%		4	28.6%
Refused	100	8.8%		0	0.0%
Total Sample	1152	100.0%	Total Interviewed	377	32.7%

Since the number of Hispanic/Latino caregivers was quite small, an attempt was made to supplement the sample size by adding 14 Hispanic/Latino caregivers from the state of California who had used demonstration respite services, but had not been subsidized with demonstration funds. With the addition of these 14 subjects, seven of which completed the interview, the total sample size for the study was 377. Demographic information was collected from the supplemental sample of Hispanic/Latino caregivers at the time of interview. The distribution of the sample by state and ethnicity is depicted in Table 1.2.

Data Collection

Data pertaining to the demographic characteristics of caregivers and elders were taken from the information collected at the point of intake for each family participating in the ADDGS program. Additional data pertaining to caregivers' beliefs and attitudes and their views concerning aspects of service delivery were obtained through structured telephone interviews. Specifically, in the

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fall of 1999, twenty minute telephone interviews were conducted with 377 client caregivers from the ADDGS. Caregivers were asked about their experiences with demonstration services, their satisfaction with services, their views on caregiving, and their experiences providing care. Interviews were conducted using a computer assisted telephone interview (CATI) system that allowed for simultaneous data entry of the responses during the interview process.

TABLE 1.2. DISTRIBUTION OF SAMPLE BY STATE AND RACE (N=377)

	V	/hite	Black/Afr	r-American	Hisp	/Latino	All G	roups
	N	%	N	%	N	%	N	%
California	_	0.00/	•	0.00/		40.00/	40	4.4.407
California	5	3.0%	0	0.0%	38	40.9%	43	11.4%
Washington D.C.	1	0.6%	25	21.6%	3	3.2%	29	7.7%
Florida	18	10.7%	31	26.7%	30	32.3%	79	21.0%
Maine	48	28.6%	0	0.0%	0	0.0%	48	12.7%
Michigan	33	19.6%	15	12.9%	1	1.1%	49	13.0%
North Carolina	18	10.7%	19	16.4%	2	2.2%	39	10.3%
South Carolina	44	26.2%	24	20.7%	0	0.0%	68	18.0%
Washington	1	0.6%	2	1.7%	19	20.4%	22	5.8%
Total	168	44.6%	116	30.8%	93	24.7%	377	100.0%

Measures

Items included in the questionnaire (see Appendix 1B) were carefully screened prior to inclusion. Some items were included because they provided important information about the demographic and background characteristics of the participants. Other items were included because they were intended to measure client beliefs and attitudes about family care responsibilities and the appropriateness of using formal support services. Whereas a single item can usually be used to assess respondent demographic characteristics reliably (e.g., gender or ethnicity), multiple items are generally required to reliably assess concepts such as caregiver beliefs, accessibility of services, and client satisfaction. Consequently, multiple items from the interview instrument were used to create measures of the key concepts related to

caregiver beliefs about family care, accessibility of services, and satisfaction with services (see Appendix 1C).

The first phase of data analysis entailed the development of reliable measures for each of the key concepts using items included in the interview schedule. This evaluation involved several steps. First, the pattern of frequencies of responses was examined for each item. Questions were not asked of subgroups of respondents when not applicable. As a result of these "skip patterns," different sample sizes were obtained for different items in the interview schedule. In other cases, respondents may have been reluctant to respond to a particular question (e.g., questions about income). Decisions about how to handle such "missing data" were made in the context of the particular purpose underlying each analysis.

To increase reliability, several items were generally hypothesized to tap a common latent variable or "factor." Thus, the second step in the item analysis involved submitting the relevant items to a common factor analysis. Although there are many different techniques subsumed under the broad rubric of "factor analysis", when the questionnaire items work as hypothesized (i.e., there is a clear structure to the data), they all produce essentially the same result. The main issue is primarily a statistical one—how to construct the correlation matrix to be analyzed. The general rule in this study was to use a form of principal axis factoring (i.e., communality estimates are placed in the diagonal rather than unities) with an orthogonal rotation. (Interested readers should consult Nunnally, 1978; Widaman, 1993.)

The third step in the item analysis was to estimate the reliability of the measure created by the selected multiple items. Cronbach's alpha was used to estimate the internal consistency of each measure. The alpha coefficient can range from 0 to 1, with higher scores desirable.

Measures of Demographic and Background Variables

Eight variables were included as measures of demographic and background characteristics of elders. These demographics included *gender*, *marital status*, *income*, *age*, *geographic location*, *living arrangement*, *total residents in household*, and *number of services used prior to entry* (see Appendix 1B).

Four additional variables were included as measures of elders' functional status. These measures included *diagnostic status*, *problem behaviors*, *ADL level*, and *IADL level*.

Demographic characteristics of caregivers were assessed either at the time of intake or interview. Measures drawn from intake information included *gender*, *age*, *marital status*, *education*, *employment*, *income*, *length of caregiving before program entry*, and *driving distance from elder*. Caregivers' *relationship to elder*, *number of persons in household*, *help provided by elder*, and *availability of a back-up caregiver* were collected as part of the interview.

Four characteristics of caregivers' health and well-being rounded out the demographic and background characteristics. The interview schedule included items about *life satisfaction*, physical health, and detriment to work while caregiving. A measure of the degree of depressive symptomology was also included in the interview.

Measures of Caregiver Beliefs

Eleven composite variables were constructed to measure aspects of caregivers' beliefs about aging and responsibilities for care. These measures included affection for elder, obligation to care, family values, respect for elders, desired frequency of social contact, guilt at respite use, attitudes toward government assistance, satisfaction with help with caregiving, religiosity, strength of beliefs, and support provided by religious congregation. The individual items used to create the composite measures are listed in Table 1.3 along with the estimated reliability of each measure.

Measures of Access/Barriers

Nine composite variables were constructed to measure caregivers' perceptions of access and/or barriers to service use. These included *client satisfaction, communication difficulties, clear expectations, access to services, friendliness of staff, shared values with staff, institutional barriers, trust in staff, and appropriateness of activities.* Individual items for each of these measures and the estimated reliability for each measure are listed in Table 1.4.

TABLE 1.3. MEASURES OF CAREGIVER BELIEFS AND ATTITUDES

FAMILY RELATIONSHIPS Affection for Elder ^A 1. I am extremely close to my [relative]. 2. I have great affection for my [relative]. 3. I have a strong attachment to my [relative]. 4. I am completely devoted to my [relative]. 5. I love my [relative]. 6. I genuinely like my [relative]. Obligation to Care ^A 1. It is my duty to care for my [relative]. 2. I personally must protect my [relative]s interests. 3. I feel I have to assume caregiving tasks for my [relative]. 4. I am morally bound to care for my [relative]. 5. It is my obligation to help my [relative]. 6. I am responsible for my [relative]. 7. When someone has problems, s/he can count on help from his/her relatives. 7. People should seek the advice of older relatives in important matters. 7. A person should share his/her home with uncles, aunts, or first cousins if they are in need. 7. It is sill important to obey the wishes of parents/older relatives. 7. True wisdom comes with age. 7. One can count on help from relatives to solve most problems. 8. Aging parents should live with their relatives. 8. Aging parents should live with their relatives. 9. Certain positions of responsibility should have final say in family decisions. 9. Certain positions of responsibility should be given only to older persons. Desired Frequency of Social Contacts 1. Would you like to see or talk to your relatives more often, less often, or as often as you do now? 1. Would you like to see or talk to your friends more often, less often, or as often as you do now?	Variable	Items	Reliability
2. I have great affection for my [relative]. 3. I have a strong attachment to my [relative]. 4. I am completely devoted to my [relative]. 5. I love my [relative] very much. 6. I genuinely like my [relative]. Obligation to Care ^A 1. It is my duty to care for my [relative]. 2. I personally must protect my [relative] sinterests. 3. I feel I have to assume caregiving tasks for my [relative]. 4. I am morally bound to care for my [relative]. 5. It is my obligation to help my [relative]. 6. I am responsible for my [relative]. 7. It is my obligation to help my [relative]. 8. It is my obligation to help my [relative]. 8. It is my obligation to help my [relative]. 9. People should seek the advice of older relatives in important matters. 9. A person should share his/her home with uncles, aunts, or first cousins if they are in need. 9. It is still important to obey the wishes of parents/older relatives. 9. True wisdom comes with age. 9. If a relative told you he is in financial difficulty, you would help as much as you could. 9. One can count on help from relatives to solve most problems. 9. Aging parents should live with their relatives. 9. The oldest person in the family should have final say in family decisions. 9. Certain positions of responsibility should be given only to older persons. 9. Would you like to see or talk to your relatives more often, less often, or as often as you do now? 9. Would you like to see or talk to your friends more often,	FAMILY RELATIONSHIPS		
3. I have a strong attachment to my [relative]. 4. I am completely devoted to my [relative]. 5. I love my [relative] very much. 6. I genuinely like my [relative]. Obtligation to Care ^A 1. It is my duty to care for my [relative]. 2. I personally must protect my [relative] interests. 3. I feel I have to assume caregiving tasks for my [relative]. 4. I am morally bound to care for my [relative]. 5. It is my obligation to help my [relative]. 6. I am responsible for my [relative]. 7. It is my obligation to help my [relative]. 8. It is my obligation to help my [relative]. 9. People should seek the advice of older relatives in important matters. 9. People should seek the advice of older relatives in important matters. 9. A person should share his/her home with uncles, aunts, or first cousins if they are in need. 9. It is still important to obey the wishes of parents/older relatives. 9. True wisdom comes with age. 9. If a relative told you he is in financial difficulty, you would help as much as you could. 9. One can count on help from relatives to solve most problems. 9. Aging parents should live with their relatives. 9. Aging parents should live with their relatives. 9. Certain positions of responsibility should have final say in family decisions. 9. Certain positions of responsibility should be given only to older persons. 9. Would you like to see or talk to your relatives more often, less often, or as often as you do now? 9. Would you like to see or talk to your friends more often,	Affection for Elder ^A	I am extremely close to my [relative].	0.89
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TABLE 1.3. MEASURES OF CAREGIVER BELIEFS AND ATTITUDES

(continued)

Variable	(continued)	Reliability
ATTITUDES REGARDING HE	======================================	
Guilt at Respite Use ⁵	 My family thinks less of me if I use respite for my [relative]'s care. My family doesn't think we should use respite services for our [relative]. People outside my family would think less of me if they knew that I used respite services. 	0.68
Attitudes toward ⁸ Government Assistance	 The government should provide more money for respite services. The government should help families care for persons at home. 	0.76
Satisfaction with Help ^C with Caregiving	 How satisfied are you with the amount of help you receive from others in assisting your [relative]? How satisfied are you with the amount of emotional support you have received from others in the past 6 months? 	0.71
ATTITUDES REGARDING RE	ELIGION	
Religiosity ^E	 Religion is a source of great strength and comfort to you. You try hard to carry your religious beliefs over into all your other dealings in life. You consider yourself to be a very spiritual person. 	0.84
Strength of Beliefs ^F	 You look to God for strength, support, and guidance in crises. You try to find the lesson from God in crises. 	0.91
Support from Religious ^{G,H} Congregation	 How often do people in your congregation listen to you talk about your private problems and concerns?^G How often do the people in your congregation express interest and concern in your well-being?^G If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you?^H 	0.77
Response Set B = (1) not at all true; Response Set C = (1) very dissatisfi Response Set D = (1) more often; (2 Response Set E = (1) strongly disag Response Set F = (1) not at all; (2)	ree; (2) disagree; (3) agree; (4) strongly agree somewhat; (3) quite a bit; (4) a great deal ce in awhile; (3) fairly often; (4) very often	e

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Sample Characteristics

Elder Characteristics

Demographic characteristics are shown separately for White, Black/African-American, and Hispanic/Latino elders in Table 1.5. The majority of elders in all ethnic groups were females with an average age of approximately 79 years. Black/African-American elders differed from the other groups in their marital status. Just over half (54.2%) of the White elders were married; 41.7% were widowed. In contrast, only 29.3% of Black/African-Americans and 41.9% of Hispanic/Latino elders were married. Widows or widowers comprised 56.9% of the Black/African American sample and 46.2% of the Hispanic/Latino sample.

Elders of all ethnic groups were concentrated in the lower end of the income spectrum, but differences existed among the three ethnic groups. White elders were more likely than Blacks/African-Americans to have average incomes that exceeded \$15,000. Hispanic/Latino elders were considerably less likely than Black/African-American elders to occupy higher income strata.

Group differences were also observed in geographic location. A greater proportion of Hispanic/Latino elders resided in urban or suburban areas than did Black or White elders. This difference likely reflects the focus of the ADDGS grant on serving urban minority and rural caregivers, and highlights the fact that geographic location and minority status are not independent of one another. Living arrangements varied among the three groups. While only a small proportion of elders in any of the groups lived alone, Hispanic/Latino elders (8%) were least likely, and Black/African-American elders (14%) were most likely to live alone. A larger segment of Hispanic/Latino elders resided in households of four or more persons than did elders of other ethnicities. There were differences among groups in the relationship of the elder to his/her housemates as well. A greater proportion of Whites (54%) resided with a spouse than was true for either Black/African-American (34%) or Hispanic/Latino (36%) elders. Hispanic/Latino elders were more likely than Whites to reside with an adult child or child-in-law. Black/African-American elders (11%) were more likely than members of the other two ethnic groups to live with a person other than a spouse or child, which is a reflection of the lower rates of marriage shown in the Black/African-American elder population (29%). With more than half (55%) of the Hispanic/Latino elders reporting no use of support services prior the demonstration

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services, they were less likely than other groups to have used support services prior to their entry into the demonstration.

Variations in elders' functional status showed similar patterns, as illustrated in Table 1.6. The mean ADL and IADL scores for Black/African-American elders were somewhat lower than those of White and Hispanic/Latino elders, indicating a higher functional level. Similarly, Black/African-American elders in this sample also differed from the other groups in the prevalence of

TABLE 1.4. MEASURES OF CLIENTS' VIEWS OF SERVICES

Variable	Items	Reliability
Client Satisfaction ^B	In general, I am satisfied with the care my [relative] receives.	0.84
	2. I am satisfied with the respite program services.	
	3. I would recommend this service to others.	
Communication ^{B,I,J}	When the respitve workers discuss my [relative]'s health	0.59
Difficulties	and care needs with me, they use words I understand. ^B	
	2. How easy is it for you to talk with the respite workers? ¹	
	 When talking with the respite worker, how difficult is it to explain what help you want?^I 	
	4. Workers at the respite program speak your language. ^J	
Clear Expectations ^B	The information that I received about the program	0.65
	gave me a clear idea of what to expect from the workers.	
	2. It was made clear to me exactly what the respite worker	
	would and would not do.	
	3. The service workers from the respite program understand	
	how I think.	
Access to Services ^B	Respite is readily available when I need it.	0.76
	2. It is easy to increase the amount of service we receive.	
	3. We can get the amount of respite care that we need.	
Friendliness of Staff ^{J,B}	1. The workers are welcoming and friendly to you. J	0.65
(1-2)1 = never true -	2. The workers are disrespectful. ^J	
5 = always true $(3-4)1 = $ not at all true -	 Program staff speak you my [relative] and myself in a considerate manner.^B 	
5 = extremely true	 The program staff members are respectful of my [relative]'s cultural heritage.^B 	

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TABLE 1.4. MEASURES OF CLIENTS' VIEWS OF SERVICES

(continued)

Variable	<u>Items</u>	Reliability
Shared Values ^B with Staff	The program workers take into account my [relative]'s cultural preferences. The workers characteristics about how family more has a contract to the	0.80
	The workers share my views about how family members should treat each other.	
	The respite workers take care of my [relative] the way I want them to.	
Redtape ^{B,I,J} (1-5)1 = never true -	You have to wait too long in the program office when you need to see someone.	0.59
5 = always true	2. Your [relative] complains about using the services.	
•	 It is difficult to get the respite services your [relative] needs because you do not know where to find them.^J 	
(6-7)1 = not at all - 5 = extremely	You have to wait too long to get an appointment to get the services you need. You have to wait too long to get an appointment to get the services you need. You have to wait too long to get an appointment to get the services you need. You have to wait too long to get an appointment to get the services you need.	
(8-11)1 = not at all true -	5. You lose pay from work when you use the respite services. J	
5 = extremely true	6. How reasonable is the service fee for your family budget?	
•	7. How convenient were the times respite was offered?	
	8. The application process for the program is very difficult. ^B	
	9. It takes a great deal of effort for me to use this program. ^B	
	10. It is easy to decrease the amount of service we receive. ^B	
	11. It is difficult to change the times that respite is available. ^B	
Trust in Staff ^B ₁	I trust program staff to be alone with my [relative].	0.82
	I trust program workers to be in my home or with my [relative] when I am not there.	
	3. The program workers are careful with my possessions.	
	4. Program staff are respectful of my home and my things.	
Appropriateness of ^B ₂	The respite workers plan activities that are appropriate	0.61
Activities	for my [relative].	
	2. The program staff serve familiar meals for my [relative].	
	My [relative] is familiar with the music/songs that the	
	respite workers choose.	
	caregivers who used in-home respite.	
	caregivers who used day care / group respite.	
Response Sets:		
• , ,	true; (2) a little true; (3) somewhat true; (4) quite a lot true; (5) extrem	ely true
Response Set I = (1) not at all;	(2) a little; (3) somewhat; (4) quite a lot; (5) extremely	

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Response Set J = (1) never true; (2) rarely true; (3) sometimes true; (4) frequently true; (5) always true

problematic behaviors, which were measured at the time of intake with a 15-item inventory (described in detail in Appendix 1C). Black/African-American caregivers reported significantly fewer problem behaviors, indicating less impairment. The mean problem behavior score for Hispanic/Latino caregivers was 15.4, which was higher than that of both White caregivers (13.5) and Black/African-American caregivers (10.8).

TABLE 1.5. DEMOGRAPHIC CHARACTERISTICS OF ELDERS BY RACE (N=377)

	All G	roups	W	/hite	Black/Africa	an-American	Hispa	nic/Latino
	377	100%	168	44.6%	116	30.8%	93	24.7%
	Ν	%	Ν	%	N	%	Ν	%
Gender								
Male	111	29.4%	55	32.7%	29	25.0%	27	29.0%
Female	266	70.6%	113	67.3%	87	75.0%	66	71.0%
*Marital Status								
Single	18	4.8%	3	1.8%	5	4.3%	10	10.8%
Married	165	43.8%	91	54.2%	34	29.3%	39	41.9%
Widowed	177	46.9%	70	41.7%	66	56.9%	43	46.2%
Other	17	4.5%	4	2.4%	11	9.5%	1	1.1%
*Average Income								
Under \$5,000	150	39.8%	79	47.0%	35	30.2%	33	35.5%
\$5,000 - \$15,000	194	51.5%	77	45.8%	77	66.4%	44	47.3%
\$15,001 - \$30,000	6	1.6%	5	3.0%	1	0.9%	0	0.0%
\$30,001 - \$50,000	1	0.3%	0	0.0%	0	0.0%	0	0.0%
Over \$50,000	0	0.0%	1	0.6%	0	0.0%	0	0.0%
Unknown	26	6.9%	6	3.6%	3	2.6%	16	17.2%
Mean age	7	8.9	7	9.7	78	3.2	,	78.2
*Geographic Location								
Urban	191	50.7%	51	30.4%	70	60.3%	70	75.3%
Rural	153	40.6%	106	63.1%	39	33.6%	8	8.6%
Unknown	33	8.7%	11	6.5%	7	6.0%	15	16.1%
*Living Arrangement								
Live Alone	40	10.6%	19	11.3%	16	13.8%	7	7.5%
Live with Spouse	158	41.9%	90	53.6%	39	33.6%	33	35.5%
Live with Children	141	37.4%	49	29.2%	48	41.4%	39	42.0%
Other	29	7.7%	10	6.0%	13	11.2%	5	5.4%
Unknown	9	2.4%	0	0.0%	0	0.0%	9	9.7%

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TABLE 1.5. DEMOGRAPHIC CHARACTERISTICS OF ELDERS BY RACE (N=377)--Continued

	All C	All Groups		/hite	Black/Afric	an-American	Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
*Total Number in Hou	ısehold							
Live Alone	40	10.6%	19	11.3%	16	13.8%	7	7.5%
Elder + 1 other	166	44.0%	88	52.4%	46	39.7%	30	32.5%
Elder + 2 others	85	22.5%	42	25.0%	28	24.1%	17	18.3%
Elder + 3 or more	75	19.9%	18	10.7%	26	22.4%	29	31.2%
Other/Unknown	11	2.9%	1	0.6%	0	0.0%	10	10.8%
*Number of Services	Used Prior	to Entry						
0	150	39.8%	53	31.5%	43	37.1%	51	54.8%
1 - 2	198	52.5%	97	57.7%	64	55.2%	40	43.0%
3 or more	29	7.7%	18	10.7%	9	7.8%	2	2.2%

^{*} Significant differences between ethnic groups at p <= .05

TABLE 1.6. ELDER FUNCTIONAL STATUS BY ETHNICITY (N=377)

	All (Groups	٧	Vhite	Black/Africa	an-American	Hispa	nic/Latino
	377	100%	168	44.6%	116	30.8%	93	24.7%
	Ν	%	N	%	N	%	N	%
Alzheimer's Diseas	se							
Suspected	60	15.9%	21	12.5%	17	14.7%	25	26.9%
Diagnosed	274	72.7%	133	79.2%	92	79.3%	45	48.4%
Other	31	8.2%	13	7.7%	6	5.2%	13	14.0%
Unknown	12	3.2%	1	0.6%	1	0.9%	10	10.8%
*Problem Behavio	r							
Mean Score (0 - 45)	•	13.2		13.5	10	0.8		15.4
Functional Level								
Mean ADL (0 - 10)		3.8		4.1	3	.4		4.0
Mean IADL (0 - 16)		12.0		12.3	11	1.7		12.0

^{*} Statistically significant differences between ethnic groups at p <= .05

Finally, there were differences between the Hispanic/Latino group and the other two groups in the proportion of elders who were diagnosed with Alzheimer's disease. Among White elders, 79.2% were diagnosed with AD and another 12.5% were suspected to have the disease. A similar pattern was observed for Black/African-Americans, with 79.3% having an AD diagnosis and 14.7% reporting that AD was suspected. In contrast, only 48% of the Hispanic/Latino group

were diagnosed with AD, with 27% reporting the disease to be suspected. The diagnostic status was unknown for almost 11% of Hispanic/Latinos sample, in contrast to less than 1% among the other two groups.

Caregiver Characteristics

Significant differences in demographic characteristics were also observed among the ethnic groups, with the exception of gender and age of the caregivers. As shown in Table 1.7, almost three-quarters (72%) of the caregivers in all of the ethnic groups were female and the mean age was approximately 61 years. Similar to the patterns observed for the elders, a smaller proportion of the Black/African-American caregivers (51%) than of the other groups was married. Conversely, a greater proportion of the Black/African-American caregivers was single or divorced (34%).

Levels of education, employment, and income also differed by ethnicity. White caregivers had higher levels of education than did Black/African-Americans, who were in turn more educated than the Hispanic/Latino caregivers of the sample. In regard to employment, a smaller proportion of Hispanic/Latino caregivers were retired (26%), and a larger segment remained employed full-time (27%), compared to the other two groups. The differences among the three groups in income levels mirrored those among education levels. White caregivers earned more than Black/African-Americans, who earned more than Hispanics/Latinos.

Patterns of caregiving and living arrangements differed by ethnicity as well. Hispanic/Latino caregivers provided care slightly longer than Black/African-American caregivers before enrolling in the ADDGS demonstration. For all groups, the most common living arrangement was the elder living in the same household as the caregiver, although Black/African-American caregivers were more likely to live apart from the elder. This pattern likely reflects the fact that adult children were most common as caregivers among the Black/African-American sample (63%). Adult children also comprised 55% of the Hispanic/Latino group and 46% of the White caregivers. Spouses comprised only 18% of the caregivers in the Black/African-American sample and 34% of the caregivers in the Hispanic/Latino group. Other less immediate family members were more prevalent among Black/African-American caregivers (16%) than among White caregivers (5%) or Hispanic/Latino caregivers (11%).

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TABLE 1.7. CAREGIVER DEMOGRAPHIC CHARACTERISTICS BY RACE (N=377)

	All G	roups	W	/hite	Black/Afric	an-American	Hispar	nic/Latino
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
*Relationship to elder								
Spouse	131	34.7%	78	46.4%	21	18.1%	32	34.4%
Adult child / child-in-law	201	53.3%	77	45.8%	73	62.9%	51	54.8%
Other relative	38	10.1%	9	5.4%	19	16.4%	10	10.8%
Friend	7	1.9%	4	2.4%	3	2.6%	0	0.0%
Professional care manager	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Self	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Gender								
Male	106	28.1%	54	32.1%	24	20.7%	28	30.1%
Female	271	71.9%	114	67.9%	92	79.3%	65	69.9%
Age (in years)								
44 or less	46	12.2%	11	6.5%	19	16.4%	16	17.2%
45 - 54	60	15.9%	29	17.3%	19	16.4%	12	12.9%
55 - 64	73	19.4%	33	19.6%	19	16.4%	21	22.6%
65 - 74	77	20.4%	33	19.6%	32	27.6%	12	12.9%
75 - 84	57	15.1%	31	18.5%	9	7.8%	17	18.3%
Over 84	8	2.1%	7	4.2%	0	0.0%	1	1.1%
Unknown	56	14.9%	, 24	14.3%	18	15.5%	14	15.1%
*Mean age		0.9		63.5		8.2		59.7
*Marital Status								
Single/Divorced	80	21.2%	20	11.9%	39	33.6%	18	19.4%
Married	260	69.0%	139	82.7%	59	50.9%	66	71.0%
Widowed	28	7.4%	6	3.6%	15	12.9%	6	6.5%
Unknown	9	2.4%	3	1.8%	3	2.6%	3	3.2%
*Education								
Less than high school	79	21.0%	23	13.7%	24	20.7%	31	33.3%
Completed high school	94	24.9%	42	25.0%	36	31.0%	16	17.2%
Vocational training	19	5.0%	10	6.0%	4	3.4%	6	6.5%
Attended college	72	19.1%	44	26.2%	20	17.2%	7	7.5%
College graduate	58	15.4%	29	17.3%	21	18.1%	10	10.8%
Graduate work	18	4.8%	11	6.5%	2	1.7%	4	4.3%
Unknown	37	9.8%	9	5.4%	9	7.8%	19	20.4%
*Employment								
Full-time	91	24.1%	38	22.6%	28	24.1%	25	26.9%
Part-time	71	18.8%	35	20.8%	17	14.7%	19	20.4%
Unemployed	39	10.3%	13	7.7%	16	13.8%	10	10.8%
Retired	142	37.7%	72	42.9%	46	39.7%	24	25.8%
Other/unknown	17	4.5%	7	5.4%	7	9.8%	3	15.1%
Unknown	17	4.5%	3	1.8%	2	1.7%	12	12.9%

^{*} Significant differences between ethnic groups at p <= .05

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TABLE 1.7. CAREGIVER DEMOGRAPHIC CHARACTERISTICS BY RACE (N=377)--Continued

	All Groups		White		Black/African-American		Hispanic/Latino	
	377	100%	168	44.6%	116	30.8%	93	24.7%
	N	%	N	%	N	%	N	%
*Income								
Not Reported	81	21.5%	29	17.3%	21	18.1%	31	33.3%
Reported	296	78.5%	139	82.7%	95	81.9%	62	66.7%
Under \$5,000	44	14.9%	9	6.5%	16	16.8%	16	25.8%
\$5,000-\$15,000	121	40.9%	48	34.5%	40	42.1%	35	56.5%
\$15,001-\$30,000	76	25.7%	47	33.8%	21	22.1%	6	9.7%
\$30,001-\$50,000	37	12.5%	23	16.5%	12	12.6%	3	4.8%
Over \$50,000	18	6.1%	12	8.6%	6	6.3%	2	3.2%
Number of Persons								
in Household								
1 person	45	11.9%	18	10.7%	9	7.8%	18	19.4%
2 persons	151	40.1%	87	51.8%	33	28.4%	31	33.3%
3 or 4 persons	116	30.8%	44	26.2%	46	39.7%	26	28.0%
5 or more persons	57	15.1%	15	8.9%	24	20.7%	18	19.4%
Unknown	8	2.1%	4	2.4%	4	3.4%	0	0.0%
*Help Provided by Elder (Mean)		1.5		1.8		1.4		1.6
Length of caregiving before program entry (in months								
0 - 6	52	13.8%	22	13.1%	19	16.4%	11	11.8%
7 - 12	36	9.5%	19	11.3%	8	6.9%	9	9.7%
13 - 24	63	16.7%	25	14.9%	29	25.0%	9	9.7%
25 - 36	52	13.8%	23	13.7%	22	19.0%	7	7.5%
37 - 72	70	18.6%	36	21.4%	11	9.5%	23	24.7%
72 or more	60	15.9%	27	16.1%	17	14.7%	16	17.2%
Unknown	44	11.7%	16	9.5%	10	8.6%	18	19.4%
Mean length of caregiving	4	12.0	2	12.7		38.9		44.7
*Back-Up Caregiver Availab	ole							
No	186	49.3%	92	54.8%	43	37.1%	51	54.8%
Yes	149	39.5%	51	30.4%	57	49.1%	41	44.1%
Unknown	42	11.1%	25	14.9%	16	13.8%	1	1.1%
*Driving Distance from Elde	er (min	s.)						
Lives in same household	306	81.2%	148	88.1%	91	78.4%	71	76.3%
1 - 10	25	6.6%	7	4.2%	10	8.6%	6	6.5%
11 - 30	18	4.8%	3	1.8%	12	10.3%	2	2.2%
Over 30	2	0.5%	2	1.2%	0	0.0%	0	0.0%
Other/Unknown	26	6.9%	8	4.8%	3	2.6%	14	15.1%

^{*} Significant differences between ethnic groups at p <= .05

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There tended to be greater sharing of caregiving responsibilities among Black/African-American caregivers. More Black/African-American caregivers (49%) received help with caregiving tasks from other persons than did White (30%) or Hispanic/Latino caregivers (44%) and a higher proportion of these caregivers knew someone who could provide care in their absence. The greater availability of back-up caregivers may reflect the greater tendency for Black/African-American caregivers to live in households with three or more persons. It is also of interest to note that Black/African-American caregivers were more likely than any other group to receive assistance from the care recipient. (Assistance provided by the elder was measured by five dichotomous items that are described in Appendix 1C).

Characteristics related to caregivers' health and well-being are shown in Table 1.8. Although level of physical health was similar across groups, emotional health varied by ethnicity. Hispanic/Latino caregivers expressed more satisfaction with their lives than did Blacks/African-Americans or Whites. Black/African-American caregivers exhibited fewer symptoms of depression, as measured by the CESD depression scale (see Appendix 1C; reliability of .80), than did members of other groups.

TABLE 1.8. CAREGIVERS' HEALTH AND WELL-BEING (N=377)

	White	Black/Afr-American	Hisp/Latino	All Groups	
	168 44.6%	116 30.8%	93 24.7%	377 100.0%	
	Mean	Mean	Mean	Mean	
*Life Satisfaction	2.1	2.2	2.4	2.2	
*Depression	12.3	10.9	12.5	11.9	
Physical Health	5.7	5.6	6.0	5.7	
Detriment to Work while Caregiving	1.3	0.8	1.2	1.1	

^{*} Significant differences between ethnic groups at p <= .05

Acculturation of Hispanic/Latino Caregivers

When families enrolled in the ADDGS program, they were asked about their language preferences and their country of origin. A preference for a language other than English was

only prevalent among the Hispanic/Latino families. As shown in Table 1.9, more than threequarters of both the caregivers and elders from these families expressed a preference for using Spanish. Both groups preferred to speak Spanish, and were more proficient in Spanish than English, although caregivers were more proficient in English than were elders.

Hispanics/Latinos who cared for a parent rated their English abilities higher than did spouse caregivers. The majority of both elders (70%) and caregivers (51%) were monolingual. A larger segment of Hispanic/Latino caregivers (48%) than elders (30%) were bilingual in Spanish and English. Only one caregiver claimed fluency in three or more languages.

In regard to country of origin, the highest proportion of Hispanic/Latino elders and caregivers originated in Mexico, followed closely by Cuba. The Hispanic/Latino caregivers represented in the sample did not have a high level of acculturation into White American society, as measured by a composite of four items that asked about their ethnic preferences for friends, social

TABLE 1.9. HISPANIC/LATINO ACCULTURATION AND HERITAGE

	Hispanic	/Latino Elder	 Hispanic/La	atino Caregiver
	93	100.0%	93	100.0%
	Ν	%	Ν	%
Language of Preference				
English	19	20.4%	22	23.7%
Spanish	74	79.6%	71	76.3%
Other/Unknown	0	0.0%	0	0.0%
Number of Languages Sp	oken			
One	65	69.9%	47	50.5%
Two	28	30.1%	45	48.4%
Three or more	0	0.0%	1	1.1%
Country of Origin				
United States	22	23.7%	22	23.7%
Mexico	29	31.2%	29	31.2%
Cuba	25	26.9%	26	28.0%
Central America (not MX)	4	4.3%	5	5.4%
South America	10	10.8%	10	10.8%
Other/Unknown	3	3.2%	1	1.1%
	Mean	Stnd. Dev.	Mean	Stnd. Dev.
Language Proficiency				
English (6 - 24)	10.80	6.37	15.05	6.61
Spanish (6 - 24)	19.39	5.83	22.68	3.46
Social Acculturation				
(4 - 16)			7.33	3.10

gatherings, and visitors, based upon five-point response sets. The composite measure had a reliability of .84, and is described in more detail in Appendix 1C.

The sample of families included in the client satisfaction interview was very comparable in demographic characteristics to the sample of families included in the longitudinal analyses of respite use in Study Two (see Tables 2.9 and 2.10). The distributions of gender, marital status, age, and service use prior to the demonstration are nearly identical between the two samples. The two samples were somewhat different in income levels and geographic location. The average incomes of elders in the interview sample were more densely concentrated at lower levels than was the case in the longitudinal sample. Also, a larger segment of the interview sample than of the longitudinal sample resided in urban areas. A smaller percentage of elders in the interview sample lived alone, and more lived with adult children and in larger households. These differences are likely due to the increased prevalence of adult children as caregivers in the interview sample.

Elders' functional status was also similar, but with a few minor differences. The interview and longitudinal samples were very similar in respect to Alzheimer's diagnostic status and ADL levels. Members of the interview sample required slightly less assistance with IADL tasks, but exhibited more frequent problematic behavior.

Demographic characteristics of the caregivers included in the two study samples were also similar. Caregivers did not differ with respect to gender, age, marital status, income, length of caregiving before the demonstration, and driving distance from the elder. Adult children did, however, comprise a larger proportion of the interview sample (53%) than in the longitudinal sample (46%) in Study Two. As a group, caregivers who participated in the interview also had slightly higher average levels of educational attainment. Finally, a smaller segment of caregivers in the interview sample worked full-time, and more were retired, than were those in the longitudinal sample.

Data Analysis

To assess the cultural differences in beliefs and views of respite services initially, a series of bivariate analyses was conducted for each aspect of culture (i.e. ethnicity, geography, and relationship). Specifically, a one-way analysis of variance was performed to contrast cultural

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groups on each outcome measure of interest. If the F-test was significant, a post-hoc test was then conducted to ascertain the nature of the differences between groups. Although many types of post-hoc tests are available, they differ primarily in how they adjust the observed significance level. In the absence of *a priori* hypotheses, the post-hoc tests in this study were straightforward; multiple comparisons of means, or what Cohen and Cohen (1975) refer to as "protected t-tests". They are protected in the sense that they are only performed after the null hypothesis of "no difference among means" has been rejected at the .05 level.

As previously discussed, various elements within the study sample that comprise the notion of culture in the present study (i.e., ethnicity, urban/rural location, and relationship of the caregiver to the elder) are inter-related. For example, Hispanics/Latinos in the present sample tended to reside in urban areas. Black/African-American caregivers were proportionately more likely to be children or "others" (i.e., non-spouse, non-child caregivers) compared with White caregivers. Therefore, in addition to examining the simple bivariate relationship between some aspect of culture (e.g., ethnicity) and some outcome of interest (e.g., client satisfaction with services), it is instructive to examine these same relationships controlling for the influence of the other aspects of culture (i.e., urban/rural location and relationships).

In the tables and figures that follow, the effect of each specific element of culture on each of the outcomes of interest is reported in three ways. First, the mean scores for each dependent variable are reported for each group in Tables 1.10 and 1.12. Asterisks denote mean scores that differ significantly by group. Second, incremental F statistics are reported for each outcome variable in Tables 1.11 and 1.13. The incremental F statistics correspond to the increment in explained variance that can be attributed to the specific element of culture (i.e. ethnicity, geography, or relationship) that is under consideration. The incremental F statistic is used to test for significance of the *incremental increase in explained variance of the dependent variable* that can be attributed to an element of culture when it is added to a model that already includes the other two elements of culture. For example, the incremental F-test would address the question: "What is the effect of ethnicity on satisfaction, net of the effects of urban/rural location and relationship to the elder, on satisfaction?" Finally, if the incremental F statistic was significant, a post-hoc test was then conducted to ascertain the nature of differences among groups. Findings from the post-hoc analyses are detailed in Figures 1.2 through 1.19.

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FINDINGS

Caregivers' Beliefs and Attitudes

Findings from the bivariate analyses shown in shown Table 1.10 revealed that many differences in beliefs and attitudes were associated with ethnicity. In fact, differences between ethnic groups were found to be statistically significant for every outcome measure except caregivers' reports of family conflict. Only two differences in mean scores for beliefs and attitudes were found to be related to geographic location. Specifically, caregivers in urban areas reported higher levels of obligation and a higher adherence to traditional family values. Attitudes and beliefs concerning family relationships varied by caregivers' relationship to elder. Spouses reported both more affection for the elder and greater obligation to provide care. They also reported lower adherence to family values and less family conflict. Finally, caregivers other than spouses and children reported more agreement with the notion that the government should assist with elder care.

TABLE 1.10. DIFFERENCES IN MEANS BY CULTURE IN CAREGIVERS' BELIEFS AND ATTITUDES

	All Groups		Ethnici	ty	Geog	raphy	R	elationshi	р
		White	Black	Hispanic	Rural	Urban	Child	Spouse	Other
	N=377	N=168	N=116	N=93	N=153	N=191	N=200	N=131	N=46
	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean
FAMILY RELATIONS	HIPS								
Affection for Elder	27.8	27.3**	28.5	27.9	27.5	28.1	27.3**	28.5**	27.9
Obligation to Care	27.9	27.6	28.3	27.9	27.5*	28.3*	27.5	28.7**	27.1
Family Values	28.8	27.0**	29.3	31.5	28.0**	29.7**	29.1	27.8**	30.6
Respect for Elders	4.7	3.9	4.3	6.4**	3.9	5.2	4.5	4.8	4.8
Family Conflict	1.5	1.5	1.6	1.5	1.5	1.5	1.7	1.2**	1.8
Social Contact	0.5	0.6	0.6	0.4*	0.6	0.5	0.5	0.6	0.5
ATTITUDES ABOUT	HELP								
Guilt at Respite Use	14.3	14.6	14.4	13.8*	14.4	14.3	14.3	14.4	14.2
Government Asst.	8.5	8.2*	8.8	8.7	8.4	8.7	8.6	8.2*	9.0
Satisfaction with Help	7.3	7.1	7.0	7.9**	7.1	7.5	7.2	7.6	6.9
ATTITUDES ABOUT	RELIGION								
Religiosity	10.3	9.9**	10.7**	10.4	10.1	10.4	10.4	10.1	10.3
Strength of Beliefs	6.7	6.3	7.2*	6.6	6.6	6.8	6.8	6.5	6.6
Support from Congreg.	7.0	6.6	8.0**	6.2	7.2	6.9	6.9	6.8	7.5

^{*} Group difference significant at p <= .05 prior to controlling for covariates

^{**} Groups difference significant at p <= .01 prior to controlling for covariates

As indicated by the F-statistics shown in Table 1.11, the majority of the bivariate differences associated with each aspect of culture remained statistically significant when the effects of the other two aspects of culture were controlled. Only two differences did not retain statistical significance. The differences between urban and rural caregivers in their reported obligation to care did not persist when covariates representing ethnicity and relationship were added to the test model. Similarly, the difference between spouses and children in their expectations for governmental assistance with care did not remain when covariates representing ethnicity and geography were included in the test model.

As detailed in Figures 1.2 and 1.3, affection for elder varied by ethnicity and relationship. A higher proportion of Black/African-American (Figure 1.2) and spouse caregivers (Figure 1.3) expressed high levels of affection. Spouse caregivers also expressed more feelings of obligation to care than did caregivers of other relationships (Figure 1.4).

Differences among caregivers in expressed family values were associated with both ethnicity and geographic residence. As shown in Figure 1.5, Hispanics/Latinos had the highest scores on this measure, reflecting the highest adherence to traditional views. White caregivers expressed views that were the least traditional, with Blacks/African-Americans' views in the middle. Interestingly, the views of spouse caregivers differed significantly from adult child caregivers and other, more distant relatives. Spouses were least likely to express traditional views (Figure 1.6).

Differences in caregivers' levels of respect for elders were also associated with both ethnicity and geographic residence. Hispanics/Latinos reported significantly higher levels of respect for elders than did either of the other two groups (Figure 1.7). Similarly, persons residing in urban areas had higher scores on the measure of respect for elders than did caregivers residing in rural areas. *Respect for elders* differed between both ethnic and geographic groups (Figures 1.7 and 1.8). The amount of *family conflict* caregivers perceived about caregiving issues varied based upon relationship. Fewer spouse caregivers reported familial conflict than did adult children or other relatives (Figure 1.9).

TABLE 1.11. TESTS FOR DIFFERENCES IN CAREGIVERS' BELIEFS AND ATTITUDES BY MEASURES OF CULTURE

		Incremental F Statistics	
	Ethnicity ^A	Geography ^B	Relationship ^c
FAMILY RELATIONSHIPS			
Affection for Elder	4.9*	0.0	7.5*
Obligation to Care	2.4	2.6	9.7*
Family Values	17.3*	0.0	3.6*
Respect for Elders	30.8*	3.9*	1.8
Family Conflict	0.6	0.2	11.1*
Social Contact	3.2*	0.0	1.2
ATTITUDES REGARDING HE	LP		
Guilt at Respite Use	6.7*	1.7	0.1
Government Asst.	3.6*	0.0	2.0
Satisfaction with Help	7.1*	0.0	1.6
ATTITUDES REGARDING RE	LIGION		
Religiosity	4.2*	0.2	0.0
Strength of Beliefs	7.0*	0.0	0.6
Support from Congreg.	8.1*	1.8	0.9

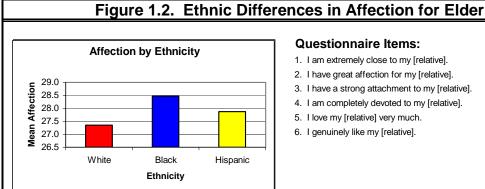
^{*} Significant differences between ethnic groups at p <= .05

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^ACovariates included in model: Relationship, Geographic Location

^BCovariates included in model: Ethnicity, Relationship

^CCovariates included in model: Ethnicity, Geographic Location



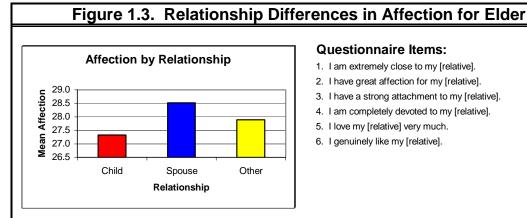
Mean Affection 28.5 - 2.85 - 27.5 - 27.0 - 26.5					
5 20.5					
28.0 -					
₹ 27.5 -					
8 27.0 -					
ĕ 27.0 ∃					
≥ _{26.5} -					
	White	Black	H	Hispanio	;
		Ethnicit	У		

Report			
Ethnicity	N	Mean	Std. Dev.
White	168	27.3	4.0
Black	116	28.5	2.8
Hispanic	93	27.9	3.2
Total	377	27.8	3.5

- 1. I am extremely close to my [relative].
- 2. I have great affection for my [relative].
- 3. I have a strong attachment to my [relative].
- 4. I am completely devoted to my [relative].
- 5. I love my [relative] very much.
- 6. I genuinely like my [relative].

Statistics for Difference

Bivariate F 3.7 4.9 Incremental F p < .01Significance Level Source of Difference: Black > White



Report			
Relationship	Ν	Mean	Std. Dev.
Child	200	27.3	3.8
Spouse	131	28.5	3.0
Other	46	27.9	3.0
Total	377	27.8	3.5

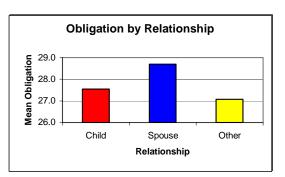
Questionnaire Items:

- 1. I am extremely close to my [relative].
- 2. I have great affection for my [relative].
- 3. I have a strong attachment to my [relative].
- 4. I am completely devoted to my [relative].
- 5. I love my [relative] very much.
- 6. I genuinely like my [relative].

Statistics for Difference

4.7 Bivariate F 7.5 Incremental F Significance Level p < .01Source of Difference: Child < Spouse





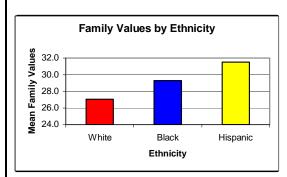
Report			
Relationship	Ν	Mean	Std. Dev.
Child	200	27.5	3.3
Spouse	131	28.7	2.3
Other	46	27.1	4.1
Total	377	27.9	3.2
•	· · · · · · · · · · · · · · · · · · ·	·	•

- 1. It is my duty to care for my [relative].
- 2. I personally must protect my [relative]'s interests.
- 3. I feel I have to assume caregiving tasks for my [relative].
- 4. I am morally bound to care for my [relative].
- 5. It is my obligation to help my [relative].
- 6. I am responsible for my [relative].

Statistics for Difference

 $\begin{tabular}{ll} Bivariate F & 7.2 \\ Incremental F & 9.7 \\ Significance Level & p < .01 \\ Source of Difference: Spouse > Child and Other \\ \end{tabular}$

Figure 1.5. Ethnic Differences in Family Values



Report			
Ethnicity	Ν	Mean	Std. Dev.
White	168	27.0	5.5
Black	116	29.3	5.6
Hispanic	93	31.5	5.2
Total	377	28.8	5.8

Questionnaire Items:

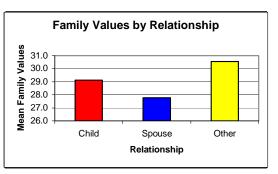
- When someone has problems, s/he can count on help from his/her relatives.
- 2. People should seek the advice of older relatives in important matters.
- 3. A person should share his/her home with uncles, aunts, or first cousins if they are in need.
- 4. It is still important to obey the wishes of parents/older relatives.
- 5. True wisdom comes with age.
- 6. If a relative told you he is in financial difficulty, you would help as much as you could.
- 7. One can count on help from relatives to solve most problems.
- 8. Aging parents should live with their relatives.

Statistics for Difference

 $\begin{array}{ll} \text{Bivariate F} & 20.4 \\ \text{Incremental F} & 17.3 \\ \text{Significance Level} & p < .01 \end{array}$

Source of Difference: Hispanic > Black; Black > White





Report			
Relationship	Ν	Mean	Std. Dev.
Child	200	29.1	5.6
Spouse	131	27.8	5.8
Other	46	30.6	6.0
Total	377	28.8	5.8

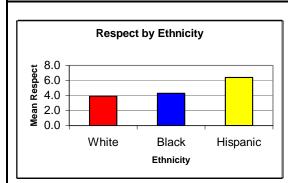
- When someone has problems, s/he can count on help from his/her relatives.
- 2. People should seek the advice of older relatives in important matters.
- 3. A person should share his/her home with uncles, aunts, or first cousins if they are in need.
- 4. It is still important to obey the wishes of parents/older relatives.
- 5. True wisdom comes with age.
- If a relative told you he is in financial difficulty, you would help as much as you could.
- 7. One can count on help from relatives to solve most problems.
- 8. Aging parents should live with their relatives.

Statistics for Difference

 $\begin{array}{ll} \text{Bivariate F} & 4.6 \\ \text{Incremental F} & 3.6 \\ \text{Significance Level} & p < .05 \end{array}$

Source of Difference: Spouse < Child and Other





ı	Report			
ı	Ethnicity	Ν	Mean	Std. Dev.
ı	White	168	3.9	1.9
	Black	116	4.3	2.1
ı	Hispanic	93	6.4	2.6
	Total	377	4.7	2.4

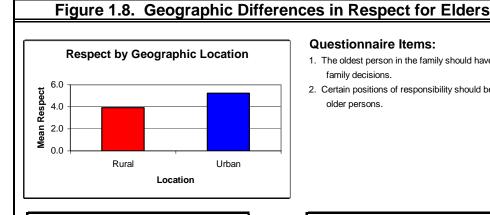
Questionnaire Items:

- 1. The oldest person in the family should have final say in family decisions.
- Certain positions of responsibility should be given only to older persons.

Statistics for Difference

Bivariate F 42.5
Incremental F 30.8
Significance Level p < .01

Source of Difference: Hispanic > Black and White

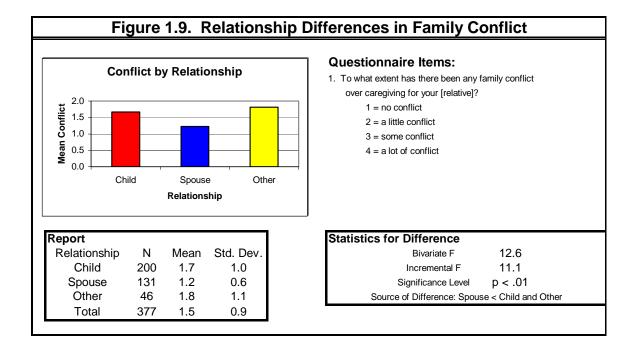


- 1. The oldest person in the family should have final say in family decisions.
- 2. Certain positions of responsibility should be given only to older persons.

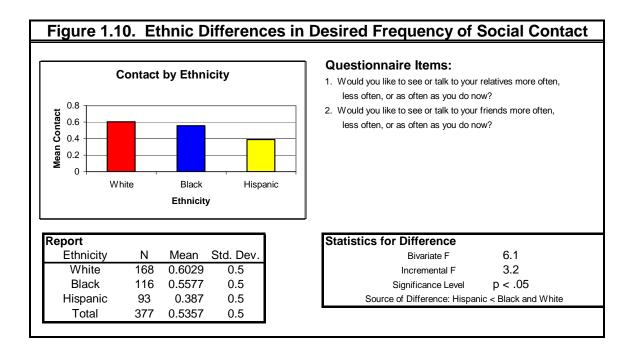
Report			
Location	Ν	Mean	Std. Dev.
Rural	153	3.9	2.0
Urban	191	5.2	2.5
Total	344	4.7	2.4

Statistics for Difference 27.5 Bivariate F Incremental F 3.9 Significance Level p < .05

Source of Difference: Urban > Rural



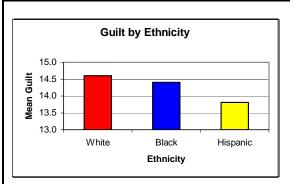
The desire for more frequent social contact differed only by ethnicity. Hispanic/Latino caregivers were most content, and Whites and Black/African-Americans less so, with their current patterns of contact. This finding is illustrated in Figure 1.10.



Groups also held differing attitudes about help with caregiving. A smaller proportion of Hispanic/Latino caregivers than caregivers from other ethnic groups felt *guilty* about using respite services, as shown in Figure 1.11. Similarly, White caregivers expressed more resistance to accepting *government assistance* than did other groups (Figure 1.12). *Satisfaction with help with caregiving* varied by ethnicity as well, with Hispanics/Latinos expressing more satisfaction with the informal help that they received than did caregivers from other ethnic groups. This finding is depicted in Figure 1.13.

Ethnic distinctions were correlated with religious differences. On average, White caregivers expressed less *religiosity* than other groups, as seen in Figure 1.14. Variation in strength of religious beliefs mirrored the patterns of religiosity. Black/African-American caregivers' beliefs were strongest, as shown in Figure 1.15. Finally, ethnic groups differed in the amount of support they received from their congregation. A larger proportion of Black/African-American caregivers than other groups felt that they received support, as Figure 1.16 illustrates.

Figure 1.11. Ethnic Differences in Guilt at Respite Use



Questionnaire Items:

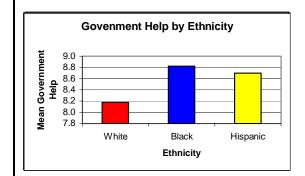
- 1. My family thinks less of me if I use respite for my [relative]'s care.
- 2. My family doesn't think we should use respite services for our [relative].
- People outside my family would think less of me if they knew that I used respite services.

Re	port			
	Ethnicity	N	Mean	Std. Dev.
	White	168	14.6	1.4
	Black	116	14.4	1.6
	Hispanic	93	13.8	2.4
	Total	377	14.3	1.8

Statistics for Difference

 $\begin{tabular}{ll} Bivariate F & 6.4 \\ Incremental F & 6.7 \\ Significance Level & p < .01 \\ Source of Difference: Hispanic < Black and White \\ \end{tabular}$

Figure 1.12. Ethnic Differences in Attitudes toward Government Assistance



uestio	

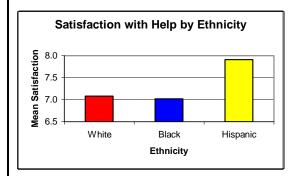
- The government should provide more money for respite services.
- 2. The government should help families care for persons at home.

Report			
Ethnicity	Ν	Mean	Std. Dev.
White	168	8.2	2.1
Black	116	8.8	1.6
Hispanic	93	8.7	1.9
Total	377	8.5	1.9

Statistics for Difference

 $\begin{tabular}{ll} Bivariate F & 4.6 \\ Incremental F & 3.6 \\ Significance Level & p < .05 \\ Source of Difference: White < Hispanic and Black \\ \end{tabular}$

Figure 1.13. Ethnic Differences in Satisfaction with Help with Caregiving

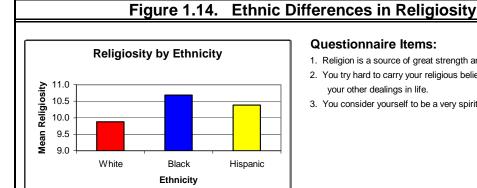


Questionnaire Items:

- 1. How satisfied are you with the amount of help you have received from others in assisting your [relative]?
- 2. How satisfied are you with the amount of emotional support you have received from others in the last 6 months?

R	eport			
	Ethnicity	N	Mean	Std. Dev.
	White	168	7.1	2.0
	Black	116	7.0	2.0
	Hispanic	93	7.9	2.1
	Total	377	7.3	2.0

Statistics for Difference 6.4 Bivariate F 7.1 Incremental F p < .01Significance Level Source of Difference: Hispanic > White and Black



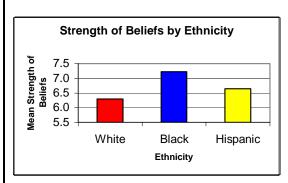
Questionnaire Items:

- 1. Religion is a source of great strength and comfort to you.
- 2. You try hard to carry your religious beliefs over into all your other dealings in life.
- 3. You consider yourself to be a very spiritual person.

Report			
Ethnicity	Ν	Mean	Std. Dev.
White	168	9.9	2.1
Black	116	10.7	1.7
Hispanic	93	10.4	1.7
Total	377	10.3	1.9

Statistics for Difference Bivariate F 6.5 Incremental F 4.2 Significance Level p < .01Source of Difference: White < Black and Hispanic





Questionnaire Items:

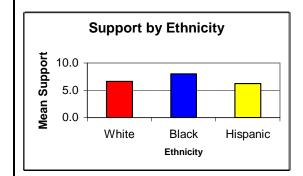
- You look to God for strength, support, and guidance in crises.
- 2. You try to find the lesson from God in crises.

Report			
Ethnicity	N	Mean	Std. Dev.
White	168	6.3	1.9
Black	116	7.2	1.5
Hispanic	93	6.6	2.0
Total	377	6.7	1.8

Statistics for Difference Bivariate F 9.2 Incremental F 7.0 Significance Level p < .01

Source of Difference: Black > Hispanic and White

Figure 1.16. Ethnic Differences in Support from Religious Congregation



Questionnaire Items:

- How often do people in your congregation listen to you talk about your private problems and concerns?
- 2. How often do the people in your congregation express interest and concern in your well-being?
- 3. If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you?

Report			
Ethnicity	N	Mean	Std. Dev.
White	168	6.6	3.1
Black	116	8.0	2.4
Hispanic	93	6.2	3.0
Total	377	7.0	3.0

Statistics for Difference

 $\begin{array}{ccc} \text{Bivariate F} & 11.8 \\ \text{Incremental F} & 8.1 \\ \text{Significance Level} & p < .01 \\ \text{Source of Difference: Black > White or Hispanic} \end{array}$

Clients' Views of Services

Groups were equally satisfied with respite services, without regard to culture. Although the mean scores reflecting caregiver's assessment of communication difficulties and institutional barriers reported in Table 1.12 were different at the zero-order level, the strength of this relationship generally diminished substantially when covariates representing ethnicity, relationship, and type of services were included in analyses. No differences associated with the caregivers' relationship to the elder were observed for any of the outcome measures. Ethnicity and service type (ADC versus In-home) differences were initially observed on only three measures (Table 1.12). As shown in Table 1.13, however, these differences remained significant only for the communication difficulties and staff friendliness after controls for other cultural characteristics and magnitude of need (ADL/IADL and problem behavior) were included in the analyses.

TABLE 1.12. DIFFERENCES IN MEANS BY CULTURE FOR CLIENT SATISFACTION AND VIEWS OF SERVICES

	All Groups		Ethnici	ty	Geog	raphy	Re	lationshi	ip	Service	е Туре	
		White	Black	Hispanic	Rural	Urban	Child	Spouse	Other	DC	INH	Both
	N=377	N=168	N=116	N=93	N=153	N=191	N=200	N=131	N=46	N=143	N=139	N=52
	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean	Mean
Client Satisfaction	13.9	13.9	14.2	13.5	14.0	14.0	13.8	14.0	14.1	14.1	14.0	13.4
Communication Difficulties	6.8	6.2	6.1	8.9**	6.2**	7.3**	6.8	7.1	6.3	6.1	6.4	7.4*
Clear Expectations	13.3	13.2	13.4	13.2	13.1	13.5	13.2	13.4	13.5	13.2	13.4	12.6
Access to Services	10.8	10.1*	11.1	11.7	10.5	11.1	10.6	11.0	11.3	11.2*	10.2	9.7
Staff Friendliness	19.2	19.4	19.3	18.8**	19.3	19.2	19.2	19.1	19.6	19.4	19.2	19.0
Shared Values	13.7	13.7	13.8	13.6	13.7	13.8	13.6	13.7	14.0	13.8	13.8	13.0
Institutional Barriers	10.9	10.6	10.7	11.8*	10.4**	11.5**	11.1	10.9	10.2	10.7	10.6	11.5
Trust in Staff ¹	18.6	18.8	18.9	18.0*	19.0	18.6	18.6	18.6	18.9	~	18.9	17.8
Appropriate Activities ²	13.0	13.1	13.4	12.5	13.1	13.1	12.9	12.7	13.7	13.3	~	12.0

^{*} Group difference significant at p <= .05 prior to controlling for covariates

^{**} Group difference significant at p <= .01 prior to controlling for covariates

¹ This question was only asked of those that used in-home respite.

This question was only asked of those that used day care / group respite.

A larger proportion of Hispanic/Latino caregivers reported greater difficulty with communication relative to other groups (Figure 1.17). Also, caregivers who utilized both day care and in-home respite services expressed more difficulty with communication than did users of only one service (Figure 1.18). Perceptions of *access to services* also varied by ethnicity. Accessibility was rated lowest by White caregivers (Figure 1.19).

TABLE 1.13. TESTS FOR DIFFERENCES IN CLIENTS'
VIEWS OF SERVICES BY MEASURES OF CULTURE

		Increment	tal F Statistics	
	Ethnicity ^A	Geography ^B	Relationship ^c	Service Type ^D
Olient Cetisfaction				
Client Satisfaction	0.2	0	0.3	0.2
Communication Diffs	10.8*	0.6	1.6	12.4*
Clear Expectations	0.1	1.9	1.6	0.7
Access to Services	5.7*	0.2	1.0	1.8
Staff Friendliness	1.4	0.3	2.1	0.4
Shared Values	0.2	0.3	1.2	0.9
Redtape	0.5	2.5	0.7	0.1
Trust in Staff ¹	0.2	1.7	0.3	0.6
Approp. Activities ²	0.1	0.2	2.1	0.3

^{*} Significant differences between ethnic groups at p <= .05

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¹ This question was only asked of those that used in-home respite.

² This question was only asked of those that used adult day care / group respite.

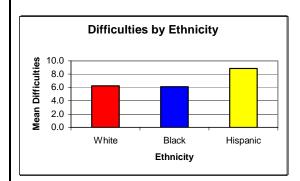
^ACovariates included in model: Relationship, Geographic Location, IADL, ADL, Problem Behavior, Respite Type

^BCovariates included in model: Ethnicity, Relationship, ADL, IADL, Problem Behavior, Respite Type

^cCovariates included in model: Ethnicity, Geographic Location, IADL, ADL, Problem Behavior, Respite Type

^DCovariates included in model: Ethnicity, Geographic Location, Relationship, IADL, ADL, Problem Behavior

Figure 1.17. Ethnic Differences in Communication Difficulties



Report			
Ethnicity	Ν	Mean	Std. Dev.
White	168	6.2	2.0
Black	116	6.1	2.3
Hispanic	93	8.9	3.6
Total	377	6.8	2.8

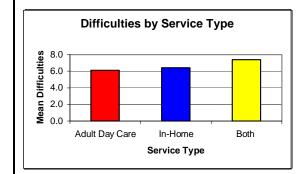
Questionnaire Items:

- When the respite workers discuss my [relative]'s health and care needs with me, they use words I understand.
- 2. How easy is it for you to talk with the respite workers?
- 3. When talking with the respite worker, how difficult is it to explain what help you want?
- 4. Workers at the respite program speak your language.

Statistics for Difference

	Bivariate F	38.6
	Incremental F	10.8
	Significance Level	p < .01
S	ource of Difference: Hispar	nic > White and Black

Figure 1.18. Service Type Differences in Communication Difficulties



Report			
Service Type	N	Mean	Std. Dev.
Adult Day Care	143	6.1	2.1
In-Home	139	6.4	2.1
Both	52	7.4	3.5
Total	334	6.8	2.8

Questionnaire Items:

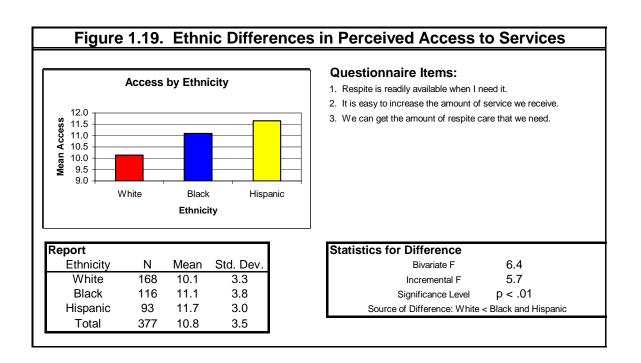
- When the respite workers discuss my [relative]'s health and care needs with me, they use words I understand.
- 2. How easy is it for you to talk with the respite workers?
- 3. When talking with the respite worker, how difficult is it to explain what help you want?
- 4. Workers at the respite program speak your language.

Statistics for Difference

Bivariate F	27.5
Incremental F	12.4
Significance Level	p < .01
Source of Difference: Both >	Adult Day and In-home

The Importance of Culture

Caregivers' beliefs and attitudes, as well as their views of services, reveal cultural differences. Members of different ethnic, geographic, and relationship groups hold markedly different beliefs about family relationships and responsibilities for care. Respite services are also perceived differently based upon type of service used and ethnicity, although the role of culture is less significant. These differences demonstrate the need for providers to consider cultural issues when developing respite programs to better address the needs of their target populations.



CLIENT SATISFACTION WITH RESPITE SERVICES

Overview

The final analyses for this study assessed the links between caregiving beliefs and attitudes and client satisfaction and between clients' views of aspects of services and client satisfaction (i.e., the two right-hand arrows depicted in Figure 1.1). Initially zero-order correlations between client satisfaction and the each of the two sets of attitude measures were examined. Findings from these initial analyses were then used to guide the development of parsimonious models for client satisfaction using multiple regression procedures. Separate models were tested for each type of respite program.¹

The Relationship Between Attitudes/Beliefs About Caregiving and Client Satisfaction

Zero-order correlations between the overall measure of client satisfaction and the 11 measures of caregivers' attitudes and beliefs about caregiving are reported in Table 1.14. As shown, seven of the measures of beliefs and attitudes about caregiving had correlations with satisfaction that were statistically significant. These measures included: (1) obligation, (2) family values, (3) desired amount of social contact, (4) government assistance, (5) satisfaction with help, (6) strength of religious beliefs, and (7) support from one's religious congregation.

Based upon these findings the measure of overall client satisfaction was regressed on this set of seven variables using Ordinary Least Squares (OLS) regression procedures. Separate analyses were conducted for the two types of respite and findings are reported in Tables 1.15 and 1.16. ²

Caregiving Beliefs as Predictors of Satisfaction with ADC

Two variables had significant, unique effects on client satisfaction in the model for day care clients: (1) as the number of desired social contacts increased, so did client satisfaction; and (2) as the amount of comfort and support from the caregiver's religious congregation increased, so did satisfaction.

TABLE 1.14. CORRELATIONS FOR CAREGIVING ATTITUDES and BELIEFS

Affection	.086	(N=332)
Obligation	.220*	(N=331)
Family Values	.192*	(N=347)
Respect	.078	(N=358)
Social Contact	.152*	(N=355)
Guilt	.063	(N=359)
Government Assistance	.114*	(N=353)
Satisfaction w/ Help	.262*	(N=327)
Religiosity	.031	(N=364)
Strength of Beliefs	.121*	(N=365)
Support from Congregation	.126*	(N=356)

^{*} p < .05

Note: The correlations are based on listwise deletion. The substantive results are unaffected when EM imputation is used for missing data.

The fact that caregivers who desired more social contact also had higher levels of client satisfaction suggests that ADC may perform a social function. That is, Adult Day Care programs may afford caregivers an opportunity for social contact—either directly by setting the occasion for interaction with respite workers, or indirectly by allowing the caregiver to use the time off afforded by respite to find outside sources for interaction. The finding that caregivers who found emotional support from their congregation were also more satisfied with ADDGS respite services is difficult to interpret. One possibility is that this relationship is due to the implicit approval for the use of such services by an important social group. Such approval may reduce the social stigma or sense of personal failure that may accompany the use of formal services, thus raising the user's satisfaction with those services. An alternate explanation is that day care centers are similar to congregations in that workers and, perhaps family members of other clients, serve as an emotional support network.

TABLE 1.15. REGRESSION OF CLIENT SATISFACTION ON CAREGIVING
ATTITUDES and BELIEFS (ADC users only)

	b/SE	Beta	t-Value	Probability
Obligation to Care	0.38/0.22	0.14	1.72	0.09
Family Values	0.12/0.11	0.09	1.04	0.30
Social Contact	2.06/0.77	0.21	2.69	0.01
Government Assistance	0.46/0.33	0.11	1.40	0.17
Satisfaction with Help	0.47/0.33	0.11	1.41	0.16
Strength of Beliefs	0.01/0.41	0.02	0.25	0.81
Support from Congregation	0.85/0.25	0.30	3.46	0.00
F Statistic		5.839		
R^2		0.23		
Degrees of Freedom		7		

TABLE 1.16. REGRESSION OF CLIENT SATISFACTION ON CAREGIVING ATTITUDES and BELIEFS (In Home users only)

	b/SE	Beta	t-Value	Probability
Obligation to Care	0.34/0.20	0.15	1.72	0.09
Family Values	0.31/0.14	0.20	2.20	0.03
Social Contact	-0.12/0.85	-0.01	-0.15	0.88
Government Assistance	0.03/0.38	0.01	0.09	0.93
Satisfaction with Help	0.93/0.38	0.21	2.44	0.02
Strength of Beliefs	0.70/0.40	0.16	1.76	0.08
Support from Congregation	-0.33/0.24	-0.13	-1.42	0.16
F Statistic		4.09		
R^2		0.18		
Degrees of Freedom		7		

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Beliefs as Predictors of Satisfaction with In-home Respite

Two indicators of caregiver beliefs also had statistically significant correlations with client satisfaction among in-home respite users: (1) as satisfaction with outside help (i.e., the amount of instrumental and emotional support received from others) increased, so did satisfaction with the ADDGS program; and (2) as the importance placed on family values by caregivers increased, so did satisfaction with the ADDGS program. Since clients who use in-home respite are generally caring for more impaired elders, instrumental support is probably the most important type of support they can receive. Hence, it has the strongest relationship to satisfaction. Also, since the respite service is performed in the caregiver's own home, the focus on family values makes intuitive sense. Care provided in the home by a respite worker will be evaluated more highly to the extent that the caregiver views it as similar to the care that he or she would provide.

Client Views of Aspects of Service Delivery and Client Satisfaction

The zero-order correlations between client satisfaction and caregiver's views about aspects of service delivery are shown in Table 1.17. All eight of the measures of clients' views about aspects of service delivery had significant correlations with the measure of client satisfaction. However, the magnitude of the correlations between client satisfaction and shared values (.75) and between client satisfaction and trust (.72) indicated that the two factors are empirically indistinct from the measure of client satisfaction. Because shared values and trust and are essentially an alternate measure of the same construct the two variables were dropped from the subsequent multivariate analyses. ³

As before, the models for ADC and in-home were analyzed separately. This was done because the model for ADC was altered to include the variable "appropriate activities". This variable was included because it had a significant zero-order correlation with client satisfaction. However, the information was only obtained from caregivers using day care programs (See Table 1.17).⁴

TABLE 1.17. CORRELATIONS FOR ASPECTS OF SERVICE DELIVERY and CLIENT SATISFACTION

Communication	316*	(N=363)
Expectations	.603*	(N=342)
Access to Services	.419*	(N=331)
Friendliness	.630*	(N=360)
Shared Values	.747*	(N=304)
Redtape	400*	(N=297)
Trust	.724*	(N=272)
(In Home Users only) Appropriate Activities (ADC Users only)	.586*	(N=223)

^{*} p < .05

Note: Correlations were calculated using listwise deletion for missing data. The substantive findings remain unchanged when estimated values are imputed for missing data.

Client Views of ADC Services and Satisfaction

Findings from the analysis for ADC are shown in Table 1.18. Three variables exerted a statistically significant, unique effect on client satisfaction: caregiving expectations, appropriateness of activities, and the amount of red tape. Specifically, when caregivers had a clear idea of what the day care workers would and would not do, client satisfaction increased. Similarly, as the perceived appropriateness of the day care activities increased, satisfaction increased as well. In contrast, as the amount of red tape associate with using the day care program decreased, satisfaction with the program increased.

TABLE 1.18. REGRESSION OF CLIENT SATISFACTION ON
ASPECTS OF SERVICE DELIVERY (ADC Users Only)

	b/SE	Beta	t-Value	Probability
Respite Activities	1.00/0.32	0.30	3.11	0.00
Clear Expectations	0.81/0.32	0.23	2.53	0.01
Access to Services	0.09/0.18	0.04	0.52	0.60
Staff Friendliness	0.51/0.44	0.09	1.17	0.24
Redtape	-0.62/0.20	-0.28	-3.05	0.00
Language Difficulties	-0.10/0.41	-0.02	-0.25	0.80
F Statistic		26.68		
R^2		0.54		
Degrees of Freedom		6		

Client Views of In-Home Services and Satisfaction

The multivariate model evaluating the relationship between clients' satisfaction and views of various aspects of service delivery for in-home respite is shown in Table 1.19. Three of the five variables exerted a statistically significant, unique effect on client satisfaction: caregiving expectations, access to services, and friendliness of the respite worker. As in the case of ADC, when caregivers had a clear idea of what the respite workers would and would not do, client satisfaction with the service was higher. Similarly, when the service was more accessible to caregivers (e.g., available at times it was most needed), satisfaction was higher. Also, as the friendliness of the in-home worker increased, satisfaction increased as well.

Final Models of Client Satisfaction with ADC and In-Home Respite

Predictors of Client Satisfaction with ADC

In the final analyses of predictors of client satisfaction for each type of respite program, all of the significant predictors of client satisfaction were included in the model.⁵ The final model tested for satisfaction with adult day care included two variables reflecting attitudes and beliefs about caregiving (*social contacts* and *support from the caregiver's religious congregation*) and three variables pertaining to client views of aspects of service delivery (*caregiver*

TABLE 1.19. REGRESSION OF CLIENT SATISFACTION ON

ASPECTS OF SERVICE DELIVERY (In Home Users Only)

			,	
	b/SE	Beta	t-Value	Probability
Clear Expectations	1.34/0.32	0.29	4.17	0.00
Access to Services	0.49/0.15	0.20	3.20	0.00
Staff Friendliness	2.57/0.42	0.43	6.06	0.00
Redtape	-0.10/0.16	-0.05	-0.67	0.51
Language Difficulties	-0.22/0.31	-0.05	-0.71	0.48
F Statistic		33.78		
R^2		0.56		
Degrees of Freedom		5		

expectations, amount of red tape, and perceived appropriateness of caregiving activities).

The final model for client satisfaction with adult day care shown in Table 1.20 explained 57% of the variance in satisfaction. Four of the five variables exerted statistically significant, unique effects on client satisfaction with Adult Day Care. Satisfaction with adult day care increased as the support and comfort received from one's religious congregation increased, when caregivers had a clear idea of what the respite workers would and would not do, when the respite service was more accessible to caregivers (e.g., available at times it was most needed), or when the amount of red tape went down.

Predictors of Client Satisfaction with In-Home Respite

The final model tested for satisfaction with in-home respite included two measures of attitudes and beliefs about caregiving (satisfaction with the amount of help or support received from others and importance placed on family values by caregivers) and clients views on three aspects of service delivery (caregiver expectations, access to services, and friendliness of staff).

TABLE 1.20. FINAL MODEL OF CLIENT SATISFATION

(ADC Users Only)

0.01
0.71
0.01
0.00
0.00

TABLE 1.21. FINAL MODEL OF CLIENT SATISFATION

(In Home Users Only)

	b/SE	Beta	t-Value	Probability
		Dela	t-value	1 TODADIIITY
Clear Expectations	1.43/0.31	0.31	4.62	0.00
Satisfaction with Help	0.23/0.27	0.05	0.85	0.40
Family Values	0.03/0.10	0.02	0.30	0.77
Access to Services	0.48/0.15	0.20	3.30	0.00
Staff Friendliness	2.69/0.41	0.45	6.55	0.00
F Statistic		35.81		
R^2		0.57		
Degrees of Freedom		5		
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The final model of client satisfaction with in-home respite is shown in Table 1.21. The set of five covariates explained 57% of the variances in client satisfaction. Three variables exerted statistically significant, unique effects on client satisfaction: caregiving expectations, access to services, and friendliness of staff. As the level of each of these factors increased, so did client satisfaction with in-home respite.

Discussion and Implications for Service Delivery

Effect of Culture on Client Satisfaction

The purpose of Study One was to evaluate the role of culture in relation to client satisfaction. For this study, culture was defined in terms of three variables: ethnicity, family relationship, and geographic location. In theory, culture can affect client satisfaction either directly or indirectly through the two sets of intervening variables shown in Figure 1.1. Findings from this study, however, indicate no discernible direct effect in the present data. Nor, strictly speaking, is there a discernible indirect effect of culture on client satisfaction. That is not to say that findings, that the two sets of intervening variables (1) caregiving beliefs and attitudes, and (2) clients' views of aspects of services are unimportant. Rather, the findings suggest that many of these variables influence client satisfaction and that service providers can profit greatly from these understandings regardless of the cultural background of the client populations that they serve.

Adult Day Care

Perhaps the most significant finding from this study of client satisfaction is that many of the important predictors of client satisfaction are factors that are actually under the control of practitioners. In the final model for ADC (Table 1.20), three such factors had significant, unique effects on satisfaction: (1) providing a clear understanding to caregivers about what the day care program will and will not do in the way of providing care for the individual with AD; (2) reducing the amount of red tape for caregivers associated with using the day care program; and (3) providing day care activities that caregivers believe to be appropriate for their family members.

These findings suggest a number of direct avenues for program modification that day care providers might consider in order to maximize client satisfaction. First, adult day care programs will need to be clearly specified in terms of what caregivers can expect and cannot expect from

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the program. Day care workers will need to be trained to convey to the caregiver clearly and unambiguously exactly which services will be provided and which will not be provided. Second, the amount of red tape matters. Things that make the service difficult to use will lower satisfaction. These barriers include waiting to see a staff member, difficulty in making an appointment with staff, and lack of flexibility in the times that the services are offered. Third, day care providers must pay attention to programming. Although professional caregivers are trained to know what caregivers "need," caregivers have strong feelings about what constitutes appropriate care for their family member. Service providers would be wise to find out about the attitudes of caregivers concerning what is appropriate for their family member. Such information can be used directly by providers either to change programming, to educate caregivers (i.e., attitude change) concerning therapeutic activities, or some combination of both approaches, to ultimately enhance client satisfaction.

The remaining predictor of satisfaction with adult day care, support from one's religious congregation, while not under the direct control of providers, may offer useful insights as well. One's religious congregation is not only a source for one's personal value system, but it also serves as a source for emotional support and social validation for one's activities. Clearly, to the extent that the use of adult day care is consistent with one's personal values, and is supported by one's religious congregation, it is likely to be more valued and thereby produce greater satisfaction with the service. Religious congregations thus offer a potentially important resource and point of intervention (e.g., information and outreach in the community) for day care providers.

In-Home Respite. The final model of client satisfaction with in-home respite (Table 1.21) offers similar opportunities for service providers. In the case of in-home respite, all three significant predictors of client satisfaction are factors over which service providers have direct control: (1) clear expectations; (2) access to services; and (3) staff friendliness.

Again, each of these findings suggests a possible avenue for program modification that in-home respite providers might consider in order to maximize client satisfaction. First, as with ADC, it is important for providers of in-home programs to clearly specify to caregivers the exact nature of their services in terms of what caregivers can and cannot expect from the program. In-home workers will need to be trained to convey to the caregiver clearly and unambiguously exactly which services will be provided and which will not be provided. Second, access to services is

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critical. Access is characterized by three features: having services available when they are needed; increasing the amount of service as needed; and generally getting the overall amount of assistance that families feel they need. The lesson is clear. Programs with arbitrary, uniform guidelines based on a "one size fits all" philosophy of care are unlikely to fit the needs of many caregivers and, consequently, result in less satisfied clients. For example, many respite programs have policies that arbitrarily limit the amount of respite that a family can use. The present findings suggest that program flexibility and responsiveness in meeting individual family respite needs is key to developing a successful service. A program that empowers caregivers in making care decisions and attends to caregivers' perceptions of how much respite they think they will need, and when they believe they will need it, will likely have more satisfied clientele. Third, friendliness of staff is clearly important. Programs, especially in-home programs, will want to make a point to create friendly and caring relationships.

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ENDNOTES

First, even though the amount of missing data on individual questionnaire items was generally quite small, the use of composite indicators substantially elevated the likelihood that any given respondent would be missing at least some information across all of the relevant questions. As a result, listwise deletion of missing data was very inefficient and resulted in an unacceptable loss of information. To retain all available data, missing values were imputed using the expectation maximization (EM) algorithm (Little and Rubin, 1989) in the multivariate analyses. This procedure has been shown to be less biased than either listwise or pairwise deletion under varying assumptions about the mechanisms responsible for item nonresponse (Arbuckle, 1996). Using this imputation procedure requires that statistical tests be interpreted cautiously due to a slight downward bias in estimates of standard errors. This occurs because the imputed values are optimal statistical estimates of the missing data. As a result, they lack the residual variability present in the observed data (Enders, 2001). The statistical tests also overestimate the true sample size and resultant degrees of freedom.

Second, as is the case with most measures of client satisfaction, the present measures were highly skewed. That is, most respondents were generally very satisfied with the services they received. A cubic transformation of the satisfaction composite provided suitable relief for non-normality in the dependent variable. This variable was then divided by a constant of 100 for ease of scaling in the regression coefficients.

- ² An analysis was conducted to determine whether the relationships between caregivers' level of satisfaction and the seven predictor variables differed according to the type of respite program used. For this analysis, the sample was restricted to only clients who used either day care or in-home care (n=282) to eliminate the potential for ambiguity of interpretation of effects for this analysis. Persons who used both services were excluded. To test for differences in models for the two types of services, a dichotomous variable representing type of respite services was added to the base model along with a set of seven interaction terms. The set of interactions explained an additional 6% of the variance in client satisfaction (F (7,266) = 2.8; p<.01) indicating that separate regression models for satisfaction with ADC and In-home respite would be more informative.
- When the correlation coefficients for shared values and trust were corrected for attenuation or measurement error (Nunnally, 1978), these estimated correlations increase to .86 and .92, respectively. The magnitude of these "corrected" correlations suggests that "shared values" and "trust" are empirically indistinct from client satisfaction (i.e., they all measure the same underlying factor). Consistent with this view is the fact that the correlation between shared values and trust is .69. When corrected for attenuation, this correlation increases to .85. Given this pattern of relationships, it is hard to escape the conclusion that shared values, trust, and client satisfaction are all measuring the same thing. Therefore, shared values and trust were dropped from the subsequent multivariate analyses.

Additional support for this decision is provided by Dutka (1994) who points out that passive performance attributes that do not measure specific, actionable characteristics

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are often highly related to customer satisfaction, not because improvements relating to these attributes will increase satisfaction, but rather because passive attributes are really just alternative measures of client satisfaction. For example, in the case of shared values, the caregiver may think: "If the respite service cares for my relative the way I do, then it must be good." In this sense, shared values may represent an alternative measure of client satisfaction, since perceptions of "quality" are frequently used to define and measure "satisfaction" (e.g., Hayes, 1992). The same logic applies to the notion of trust. That is, the two constructs, shared values and trust, differ from the other aspects of service delivery in that they are "passive" attributes of the respite service. Unlike the other aspects of service delivery in Table 1.17, shared values and trust are not under the direct control of the service providers. (See also the discussion in Appendix 1D).

- ⁴ When a set of interactions terms was added to the model to test for significant differences in the models for the two types of services, the added 1.5% of explained variance was not significant (F (5,270)= 1.71; p=.13). It is therefore important to recognize that the separate models were required because the models were specified differently (i.e., the model for ADC included an extra variable appropriate activities), **not** because the variables operated differently on satisfaction with ADC versus in-home respite.
- ⁵ Two points should be noted with respect to the final models of client satisfaction with ADC and in-home respite. First, the proportion of explained variance (.57 in both models) is fairly large. Although the magnitude of explained variance suggests very good fitting (i.e., well-specified) models, it is necessary to keep in mind that multiple regression is an optimization procedure that is designed to maximize r-square within the sample. If another sample of caregivers were drawn, there is no guarantee that the same results would be obtained. Thus, these results must be interpreted with the usual amount of caution and replication is clearly desirable.

Second, the covariates of client satisfaction have been characterized as "predictors" of satisfaction. Strictly speaking, whether a given variable is most appropriately interpreted as a cause of client satisfaction or as the result of such satisfaction is an issue that cannot be resolved with cross-sectional data. The findings of this study are based on a particular set of assumptions regarding the causal relationships between certain factors and client satisfaction (see Appendix 1D). In the absence of experimental data, these assumptions can never be completely evaluated. As a result, respite providers will want to evaluate any program modifications periodically to ensure that they are having their intended effect.

⁶ The total indirect effect of a variable is the difference obtained once the direct effect of the variable (i.e., ethnicity, family relationship, and geographic location) has been subtracted from its correlation coefficient with the outcome variable (i.e. client satisfaction; see Kerlinger and Pedhazur, 1973). None of these relationships was statistically different from zero. In other words, since the zero-order correlations were approximately zero, and the direct effects were approximately zero, the indirect effect of culture on client satisfaction in the present data are necessarily negligible as well.